Designing for Cognitive Assistance: Using Technology to Improve the Lives of People with Cognitive Decline

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The project that ultimately ended up as this thesis project began out of the necessity I felt to solve this problem, without consideration to academic pursuits. I was on academic leave at the time. A mid-project serendipitous encounter with professor Daniel Jasper inspired me to immediately reenter the program using this project. I am grateful for that encounter, and to him for this inspiration.

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The duration of the study lasted about twenty months, as measured from the initial system created in the summer of 2019. I am grateful for all the help from my brother, Jon Stebbings, in caregiving for our mother, and especially grateful

for his feedback about the effectiveness of the project. During this period, my mother went from being a recipient of assistance from the system I created, to the subject of its study. I am grateful to her for all that she has done for me. It is with mixed feelings, gratitude and sadness, that her cognitive decline was the inspiration for this project.

Thanks to everyone else who helped me. I am sure every little bit made a difference.

To mom, in memory of your beautiful mind.

Abstract

Designing for cognitive decline using a tablet-based system to support failing memory, this project aims to mitigate the consequences of cognitive decline. The study occurs across four development iterations, resulting in four fully functional prototypes, using the author's mother as the subject. The results of each iteration informs the decisions taken in the next, utilizing an agile-style methodology in its development process. Final results and observations include speculation about future applications and directions for this system.

Table of Contents

List of Figures

Introduction

The idea of consigning a parent to a facility because they can no longer mentally function on their own, separate from friends and family, seems counterintuitive to family values. Yet we all live busy lives, and when our family members require care beyond our capability, we can no longer reconcile our lives with theirs and need to make a choice. The choice is overwhelmingly institutionalized care. The default option is to engage the professionals.

This work is my search to find an alternative to the default option, the reasons behind my choices, and, more importantly, a design solution that offers an avenue of communication for people with cognitive decline and their families. It began with my vision to improve my mother's quality of life while postponing her institutionalized care. I wanted to reestablish some semblance of her former independent life when her mind was sharp and her attitude self-reliant.

This thesis documents the systems I built and utilized to support my mother as her cognitive abilities declined due to dementia. Leveraging technology, I sought to supplement my mother's declining mind by memory activation. In this paper, I describe the challenges, document the four iterations of this work, and summarize my observations.

HISTORY

Both my parents were smart, avid readers, and good at math. Although both of them worked full-time, my mother held the more stable job. She became the family breadwinner from my early teen years until they retired. Her work with medical device technology, as a technical writer, bridged the gap between engineers and doctors.

Their well-earned retirement lasted about twenty years on a lake in the woods of northern Wisconsin. It was an idyllic spot in the wild among the pines and scrub oak. The abundant wildlife called on them, the birds and the deer, and less frequently the bears and the coyotes. The loons' haunting song often pierced the middle of the night. Then it abruptly ended. My father's decline came first, and they could no longer manage living remotely. He ended up in institutionalized memory care, while my mother moved to a nearby town. Everything changed. I became my father's legal guardian, and was burdened by ongoing financial and legal responsibilities.

By 2016, we had witnessed four years of institutionalized memory care for my father's advanced case of Alzheimer's Disease. By then, my mother was already showing signs of mild cognitive decline. Alarmed by a potential 'second round,' I was determined to find an alternative.

In 2017, my mother was diagnosed with general dementia. We had never explored further diagnosis to know whether it was Alzheimer's or another cognitive disease. With that diagnosis came the recommendation she should no longer drive a car. Living alone, distanced from family, and now unable to drive, coupled with dementia, my mother faced an isolation previously unknown to her. The effect of this isolation was profoundly troubling to her psyche and her cognitive decline noticeably accelerated. Family intervened and she moved into a cooperative apartment building in south Minneapolis, close to family. This allowed us to visit her often and maintain proper medical attention for her. Once established in her south Minneapolis apartment, now with frequent visits from us and developing relationships with other residents in the building, she was once again doing well.

The decline continued. Dementia is a progressive disease. Eventually, we had to step up the care. It was during this time I started wondering about using technology to assist her. She had Internet access, she had some familiarity with

computers from her work before she retired, and she still had the vestiges of her logical mind. I started searching for available digital tools or aids we could use. Surely, I thought, there had to be something available. I was incredulous to discover very little. With my background in software development, including the building of applications, it was straightforward for me to imagine a few possibilities. I was thinking about something tablet-based.

PROJECT & DOCUMENT CONVENTIONS

There are four iterations to this work. Each iteration was triggered by a significant event in our lives, giving me impetus, sometimes with urgency, to take the next step. A paper prototype was made in the first iteration, based on index cards. Digital technology was introduced in the second iteration. The third and fourth iterations expand on the use of digital technology, and within this framework I experimented with the content of the message.

I reflected about the project at the conclusion of each iteration, the results of each would inform what I did in the next. The process was much like the agile processes I have used in software development (Agile Alliance, 2013), only in this project the iterations were not of fixed duration.

Following the Methods chapter, the initial challenges and problem description make up the Design Brief chapter. This chapter describes what was needed without dictating how the specifications were to be fulfilled. It is an understanding of specifications held at the start of the project. The Design Brief sets the project in motion and is followed by chapter Response One, documenting the actions I took in the first iteration, describing what I did and why. Three more response chapters follow in similar format. Each response chapter documents what I did, how I went about it, and the observations and results that came out of the work. Iterations end with a better understanding of the problem and updates to the specifications. These updates inform the responses in each succeeding iteration.

This is like in agile software development: at the end of an iteration the scrum-master asks, “What did we learn?” The answers to this question inform the next-steps of the project. The fourth response chapter also concludes with updates and next-steps, suggesting a fifth iteration. These final next-steps can be addressed outside the scope of this thesis.

In the next chapter, I holistically summarize and analyze the four iterations in the chapter Review & Analysis chapter. Finally, in Conclusions and Future Expansion, I review the vision, goals, and progress of the project. I expand on the potential of this project and the system that was created, as a seed to much larger ideas.

Throughout this document I have used the term *adjunct mind* to signify the concept of employing technology outside ourselves, to assist in any mental activity. We all do this, from jotting down a grocery list to creating and using sophisticated software. The critical piece, however, is how the user effectively interacts with the technology. Otherwise, the most sophisticated system will have no benefit if its user cannot use it. As such, the challenge in this project lies with how to communicate with a user whose cognitive abilities are in decline.

When making statements about specifications in the Design Brief, and at the conclusion of each response chapter, I summarize the specifications borrowing from the Internet Engineering Task Force’s RFC-2119 which defines a handful of key words—MUST, SHOULD, MAY, OPTIONAL, etc.—in how these keywords are to be used in specifications or requirements documents. The same RFC document also advises these words are to be capitalized. I have followed these conventions in this thesis.

Related Work

In the summer of 2019, prior to the decision to build my own system, I searched for products that might work the way I had imagined. I was looking for something like a calendar but extremely minimalist. Another approach would have been to customize an existing calendaring system, like Google Calendar, to ‘skin’ it down to the bare minimum, and confine it to a single day’s view. The many calendaring applications were all too feature-rich, full of distracting elements, and not as customizable as I needed. These were inappropriate for use with dementia.

Then I broadened my search to see what other digital products were available that could help someone with dementia. Most of what I found was directed at caregivers or medical staff for dementia patients. Informational resources and apps seemed the most prevalent products of this genre, from official medical information, to more informal websites and printed materials. A good example from an academic source is from the University of Wisconsin Madison’s Center for Aging Research and Education. They offer a dementia friendly toolkit (University of Wisconsin, n.d.) consisting of published informational resources including videos. These resources focus on role-playing situations between caregiver and patient.

As part of the Dementia Services Development Centre at the University of Stirling, in Scotland, the award-winning Idris (2017) app promotes better quality of life through design-driven improvements in the lived environment. Its precursor from the same institution, the Design Audit Tool, performs similar assessments.

While the above resources are extremely valuable, these are intended to be used by caregivers. In my research, I was looking for resources to be used directly by those with cognitive decline or a dementia diagnosis. This class of product or service is less informational, especially when dealing with more extreme cases

where abilities to learn new information is further reduced. Instead, I would classify these products as triggers for what is already there in the person's mind. The goals for these products vary, from reminiscence to assistance. A project of the Minnesota Historical Society (2018), House of Memories, is an app which contains curated, research-based imagery that resonates with dementia patients, by triggering memories. This work is based on earlier work from National Museums Liverpool in 2012 (Ganga et al., 2017). Talking Mats (n.d.) is an Apple Store app supporting people with communication difficulties, by expressing how they feel in a visual way. It could possibly help someone with dementia. Piano With Songs (Better Day Wireless, Inc., n.d.) is another Apple Store app. It uses music as a therapeutic aid to relax. Using artificial intelligence, Timeless (n.d.) is an app connecting people with dementia to their caregivers by helping them remember and recognize their faces.

There is an entire class of apps which I would call brain exercise, such as Lumosity, Brain Fitness Pro, Eidetic, Elevate, and Happify (The Best of Health, 2015). Some brain exercise apps claim dementia prevention, but seem to assume reasonably functional existing cognitive ability, which I assume means mild dementia. (MindMate, n.d.) offers 'brain games' as a way of connecting family with dementia patients. (Constant Therapy, n.d.) provides language and speech therapy.

The class of applications I would consider assistive includes several projects I discovered subsequent to the development of the subject of this thesis project.

One of my mother's behaviors is to call me repeatedly throughout the day about the same issue. Apparently, this is a common trait with dementia, and to address this, Alz Calls (n.d.) is a chatbot service leveraging family and caregiver voices, using artificial intelligence to construct responses with familiar voices. Although this feature was not central to the goals for my project, this issue was a factor in increasing my mother's anxiety. Except, I learned about Alz Calls a little too late.

Finally, I found two apps from European efforts, each with aims similar to my thesis project.

Based in Denmark, Dan Mogensen's (2013) MemoClock embodies features similar to my project, such as pushing reminder messages from caregiver to patient. It appears likely this app and its web site existed when I originally searched for products to help my mother. MemoClock is billed as a clock and not a calendar or reminder system. As such, I didn't discover it at the time I needed something. I'm sure I would have been tempted to use it, however I am developing features outside of MemoClock's offerings, such as a means to automatically adjust the messaging based on day and time, ability to display a list of activities for the day, and ultimate integration with the phone (a planned feature beyond the scope of this thesis). Interestingly, the impetus to develop this app has a story similar to mine, responding to a parent's cognitive decline.

A more recent and more comprehensive effort, SMART4MD is a pan-European research project to produce a tablet-based patient-support tool directed at patients with mild dementia. Their multi-targeted goals include the management of medications and appointments, the reduction of functional decline, and monitoring the well-being of caregivers (Quintana et. al., 2020). SMART4MD shares some of the design goals as my project, however I feel its user interface is too complex for people with dementia, in my opinion. Consistent with that idea is their focus on 'mild dementia,' which is clearly stated in their documentation.

Methods and Materials

My experience as a software developer informs how I approach this project. Agile software development practice is commonly used when developing any software-based product or service. Although there are many flavors of Agile, such as Scrum or Kanban, the core tenets include using an iterative process and learning from each iteration to inform the next. Design Based Research is another iterative process often used in academic studies, such as in educational technology. This study was guided by these frameworks.

In particular, this project's four iterations each center on making a functional prototype. After each prototype was created, it was deployed into actual usage, and observations were recorded about how well it functioned. Each iteration began with my qualitative observations of what was most needed by the subject. This became the set of requirements for building the next prototype of the system. Once deployed, I looked for ways to test the system, prompting the subject in order to determine how well she adapted to or understood the changes that were made.

This project was specifically designed to help a real-world situation as its primary goal, and indeed the resulting prototypes provided benefit for its intended user. As the subject herself was in decline during this period of development, that also represented changing requirements, thereby dynamically influencing design responses. Each next iteration took into account what was learned from these observations, and then documented in this thesis.

Informal testing included inserting prompts into everyday conversations with the subject, to test her understanding of the system. More frequently, I simply observed her without prompting. I looked for answers to several questions.

- At what moments did she look at or use the system?
- When she did look at it, what got her attention?
- What cues were successful?
- Was the information helpful or confusing?
- In what ways did the system or its information help her (such as simple recall, or a reduction of anxiety, or something else)?
- What distractions existed within or around its display?

Although I was not always consistent in gleaning all of these answers for each iteration, I was able to capture a sufficiently comprehensive set of observations at the end of each iteration.

Ultimately, I want to provide relief to the subject, and to support her independent living arrangement. One basic measure of this goal is to monitor her level of anxiety throughout the experiment. Again, this was informally done, however, if something was off or she was confused, it would result in a battery of panicked phone calls to me.

DESIGN

From a design point of view, I intuitively rely on design principles I have learned throughout my graphic design studies, all of which are wonderfully captured in Universal Principles of Design (Lidwell, Holden, & Butler, 2010). The most relevant set of principles for this study are: Accessibility, Cognitive Dissonance, Consistency, Five Hat Racks, Gutenberg Diagram, Hick's Law, Hierarchy of Needs, Interference Effect, Layering, Legibility, Ockham's Razor, Performance Load, Readability, Satisficing, Signal-to-Noise Ratio, and Uncertainty Principle. In addition to these, I utilize the principles of Iteration and Prototyping at the project level.

“MATERIALS”

The first iteration was a paper prototype based on index cards marked up with sharpie markers. These were organized on a brass letter rack that had been found among the subject’s belongings.

All subsequent iterations involve a few levels of technology to run the tablet display. The tablet itself is a Samsung Galaxy Tab A 10.5 inch display, 32 GB, Wi-Fi only. This sat on a simple table-stand. A right-angle power connector minimized visual clutter. Wifi and Internet were already set up and available. Running on-tablet was the Firefox browser that served as the renderer for the display of information. Web technologies were leveraged throughout the project.

The server-side technology was deployed into the Amazon Web Services cloud (AWS). A virtual system (EC2 instance) was provisioned to run Ubuntu 18.04 Linux operating system, and NGINX web-server software was used to listen on the the standard HTTP (web) port 80; no effort was made during this project to use the secure HTTPS web port.

On-server software to run the application layer for the second and third iterations were made with the Ruby Language web framework called Sinatra. NGINX was configured to proxy web requests to and from this application.

The fourth iteration employed a Javascript web framework running on the browser on the front-end, eliminating the need for Ruby and Sinatra. The server-side API layer was then reduced to JSON files served up by the NGINX web server: a crude but effective means to simulate the API layer.

The Brief

When my family and I were faced with caring for my elderly mother with onset dementia, my first inclination was to wonder how we could help her and not readily give her over to some form of institutionalized care. I searched for what tools and services were available to help people with dementia and quickly realized the dominant mainstream approach was to hire expensive help in the form of in-home care, or to move the person into an institutional setting. Many families in this situation would simply give in to these expensive options once they reached the threshold where they felt they could no longer handle the situation themselves. Maybe our situation is no different, but I wondered what other tools could help us delay these inevitable and expensive solutions while at the same time improving her quality of life. If no adequate tools exist, then, I ask, why not create one?

This Brief first describes the motivations and the larger context for creating such tools. The Case Study demonstrates the need by outlining the personal conditions for someone who could benefit from this work. Although the details are taken from my mother's living arrangements in 2019, this case is not that different from many other people. The Problem Statement reviews the current offerings of tools for people with cognitive decline, and discusses the gap between existing tools and the needs previously outlined. Finally, the statement summarizes these ideas, focusing on how a memory-reminder system could provide benefit to someone with cognitive decline. The specifications are then summarized in a bulleted list.

PUBLIC CONTEXT

Dementia is a widespread phenomenon worldwide, affecting millions of people and their family and friends. The number of cases is growing. As a public mental

health issue, it is only going to keep getting worse. The Centers for Disease Control and Prevention estimates there were 5 million adults with dementia in the United States in 2014, and predicts there will be 14 million cases by 2060 (Centers for Disease Control and Prevention, 2019).

The story is not much different elsewhere. As of September 2020, the World Health Organization (WHO) estimates there are presently 50 million people worldwide with dementia, and 10 million new cases each year, increasing to “82 million in 2030 and 152 million in 2050” (World Health Organization, 2019). From a public health perspective these numbers burden us all, incurring tremendous cost to our health systems infrastructure. Globally, health systems costs are estimated at US$ 818 billion per year. The WHO states dementia is a top priority, and recognizes more innovation and research is needed (World Health Organization, 2019).

Heavy burdens on family caregivers often force the decision to use institutionalized care for their loved ones. Institutionalized care costs are very high. At the time of this writing the average cost in the Twin Cities is around $7,000 per month,[1] and the costs were not significantly lower for my father in Wisconsin[2] several years prior. Although means-tested financial assistance is available across the United States, the criteria make these funds available to only the lowest socioeconomic levels. Skipping the exact details, as they vary by state, the general rule of thumb is this: If you are poor, you get assistance. If you are not poor, you spend down your money until you are poor.

There is tremendous motivation to delay these high-cost options. In taking on the task of caregiving, however, families are saddled with the challenges of this type of care. In my experience, the needs of dementia patients are high and ever

[1] To be exact, $6,830.00 is what we currently pay per month for my mother’s care, starting October 2020. The other institutions we looked at were around the same price point. We compared about seven institutions before selecting.
[2] My father’s assisted living monthly cost started at $5,250.00 in 2012.

increasing. People with full-time jobs or other obligations outside the home will find this type of care increasingly more difficult as time goes on. This forces families and caregivers into a difficult situation, pitting unaffordable options against do-it-yourself caregiving, especially when the latter approach is poorly supported by a lack of good tools.

CASE STUDY

An elderly woman is living in a senior independent-living apartment building. She has her own apartment, and she also has access to common areas within the building complex where she can socialize with others. Her dementia diagnosis prescribes a few, common sense restrictions. She should not drive a car, and she should not be wandering around outside any distance from the apartment building grounds. Her family has also shut off her stove and oven for concern that she might accidentally leave a burner on. She no longer cooks for herself anyway. She sufficiently understands these conditions and is okay with them.

The woman's apartment is equipped with a phone, Internet access, and cable TV. She knows how to operate the phone to call family, mainly her two sons, and she tends to do this often to ask for help. Although she prefers to socialize with other residents in her building, she will often use the TV. She does not use the Internet.

In relatively good physical health, the woman has no regular medications. She does, however, take supplements, such as vitamins. An automated pill dispenser helps her remember to take these pills with marginal success.

Without access to the stove and little remaining interest (or ability) to cook for herself, all her meals must be prepared for her. Although many meals are prepared for service in the common dining room, the schedule is intermittent enough to be confusing to her. Other meals must be made to fill-in the gaps. Lunch during the weekdays are made by Meals on Wheels and delivered to her

apartment. Family helps out when they can, sometimes taking her out to a restaurant, other times simply cooking for her in the apartment. Family also prepares easy meals that can wait in the refrigerator. Although all required meals for each week have been figured out, the irregular meal schedule is a big source of anxiety for her. She no longer is able to track all the variations from day to day.

Her family lives nearby and are happy to help her, but they are often busy and cannot be around her every day. She is on her own for several days at a time between family visits. In spite of her dementia, she is able to live fairly independently under these conditions with the support she receives. She often relies heavily on phone calls to family, even for the most trivial things. Calls that go unanswered are another source of anxiety for her. Because of their other obligations, family members cannot always pick-up the phone.

Often, reminders will be written down, by a family member, on a scrap of paper and left by the phone. Sometimes these are written on a wall calendar. She does not always look at these notes, and sometimes they get misplaced. These reminders are about meals, visits, appointments, or about basic self-care, such as removing her dentures at night. These notes see limited success.

PROBLEM STATEMENT

The focus of this brief is looking to create tools to be used directly by the people affected by cognitive decline, such as the woman depicted in the Case Study. The goals for these tools are to promote and extend independent living activities for these people throughout their day. A secondary goal would be to enable caregivers' management of their charge. This work involves designing communications for users who are experiencing cognitive decline, so the user interface needs to guide their focus and avoid confusion.

At present, the majority of available tools are focused on supporting the caregiver, in proper recognition of their challenges. These tools are often

educational or informational materials about how to improve caregiver skills in dealing with dementia, or in support of the caregiver's emotional and physical well-being. These are important tools, but they do not directly support people with cognitive decline. Other tools are directed at people with reduced cognitive abilities, but do not assist them in their daily activities. Instead, these tools focus on brain exercise or remembering people in their lives.

Given these conditions, this brief seeks to explore how one can expand on the existing work and existing research to postpone institutionalization while sustaining a reasonable quality of life for people in cognitive decline, even with diagnosed cases of dementia.

The daily needs for someone experiencing cognitive decline are not really different from anyone else. It is about remembering what daily tasks need to be done, when to do them, and sometimes why they need to be done. The difference lies in the ability to understand and use the user interface.

Daily activities include meals, medications, various forms of self care, visits with others, and going to appointments. Someone experiencing cognitive decline might forget many of these tasks and will need to be reminded. Other activities involve seeking help, such as making phone calls. As such, phone numbers will also need to be remembered. While it may seem simple enough to write down a set of notes, reminders, a phone list, to help remember these items, as the amount of information grows, so does the cognitive load in the mind of the person experiencing decline. That will lead to confusion. Notes also can be misplaced.

Help could come from a caregiver who lives with the person with cognitive decline, or be highly available throughout the day, but the motivation of this brief would be to search for solutions that do not require this level of care. Even with this provider-patient model, the ongoing burden of care could be assuaged with

tools capable of enhancing ongoing communications to the patient. When the caregivers are remote, the need for digital tools increases.

How can tools assist someone with cognitive decline to remember their daily activities, but designed in a way concomitant to their cognitive abilities? Innovation in this area is starting to happen (Quintana et. al., 2020), but the availability of these products are limited. There are still gaps in what can be done, and in how this class of problem can be solved.

Cognitive decline reduces one's ability to remember and understand. Typically this affects older people, but increasingly cases have been seen at younger ages. Indirectly, this affects family and caregivers, leading to a decline in the quality of life for everyone involved. The costs are very high for institutional care, which adds further challenge to a family's set of options. By what means can the transition into institutionalized care be delayed? How can caregivers be supported with an improved set of tools to ease the caregiving burdens? Arriving at answers to these questions will involve an exploration of design communication for the target audience of those with cognitive decline.

Specifications for the tool:

- MUST grab sufficient attention of the person undergoing cognitive decline.
- the information on the display MUST be simply interpreted.
- the presented elements MUST be relevant, or removed from display.
- MUST support the caregiver's ongoing management of the information.
- SHOULD support real-time information management remotely, so the caregiver need not always be present with the person undergoing cognitive decline.

Response One: Index Cards

STATE OF THE WORLD

By mid-summer 2019, my brother and I were calling our mother on a daily basis to remind her of various daily events, visits, and other tasks. Often, she required multiple calls in a day. She also called us frequently, and repeatedly, for the same question or issue. In particular, she had ongoing anxieties about food and meals, and about where my brother and I were.

She would no longer write-down notes for herself, and was only able to do so with difficulty with our direction. And she would rarely refer to the notes we would leave her. Consistent with her declining cognitive abilities were declining organizational skills. As a result, notes would easily get misplaced, or pile up, or land in any number of useless conditions. The frequency of her missing an important event, a meal or a movie, was high enough that it required our family's vigilance to keep reminding her. This started to become a daily task for my brother and me, and we had to coordinate efforts in order to keep up.

Obviously, this amount of effort was not sustainable, but we endured it as much as we could because it worked for her. But then I had an upcoming overseas trip, and there was no way I could keep up this effort from 14 time zones away while also attending to the other tasks of the trip. There were also questions about phone connectivity while in the foreign country. Nor could I expect my brother to take on the full brunt of the effort. We needed a more autonomous system, something my brother could handle by himself while I was away.

RESPONSE DESCRIPTION

I devised an index card-based system, the first iteration of four. I had envisioned a more elaborate system, beyond index cards, employing technology, but the

available time did not allow for that. Starting with a paper-prototype is nevertheless considered a best practice, and using readily available materials helped to kick-start the project.

Admittedly, the index cards were quickly implemented, deployed, and tested in less than a couple of weeks. We ran with this system in-place for several months with many successes. The process of using this system with my mother informed new ideas for improvement that resulted in follow-on iterations, documented in subsequent chapters.

Description of Prototype

Using one index card per day and a consistent format, these cards were constructed with black Sharpie markers: a fine point for the bold headings, and ultra fine point for the body of the card. The information had to be presented as simply as possible. The goal was to minimize cognitive dissonance.

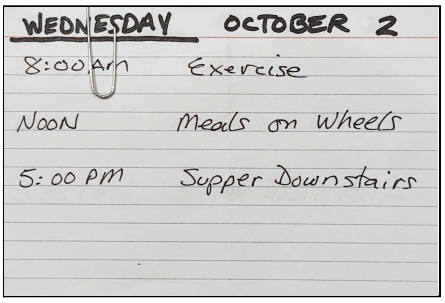

Figure 1. Example index card, October 2.

The presentation format was kept consistent from day to day, card to card. Each card was split into header and body. Day-of-the-week was the focus, as will be discussed below. As such, day-of-the-week is the very first word presented on every card, and also underlined for additional emphasis. For the remainder of the header, the month and day-of-the-month were off to the right, with secondary emphasis. Including the date helped us organize cards when we had to deal with several weeks worth, to distinguish ‘this Wednesday’ from another for example.

Although this information was intended to help the manager of the cards, it also helped its user, as a reminder of the month and day context.

The body of the card displayed what was happening that day: the reminders. The list of items, reminders, went down the body, one item per line. We were careful to avoid text-wrapping as much as possible, but there were a few exceptions. The minimal format kept to just two columns: times of the day along the left, aligned as much as possible, and the reminders to the right. I used 12-hour time with AM and PM designations, since that was more familiar to her. I also used ‘Noon’ instead of 12:00 PM, again to minimize any potential for confusion, and to help anchor the middle of the day.

Each reminder was an event, a task, or a visit. These descriptions were kept short, and the choices of words were kept to a reduced and consistent vocabulary.

Pairing

Even the best of us, on rare occasions, will doubtfully ask ourselves, “What day is it?” a moment before the answer arrives. But to expect my mother in cognitive decline to know the current day is asking a lot.

As such, we paired a display clock with the card system. The clock included all the same type of information about the current day, again displaying the day-of-the-week most prominently, to be used to compare with the card’s day-of-the-week. This was meant to orient the proper card of the day to the front of the deck, in the rack.

Figure 2. Display clock.

Figure 3. Brass card rack.

Set of Cards

For the set of cards, we had a brass letter-holder that was perfect for holding six cards: the rack. The letter rack staggered upward toward the back so you could see the top of every card. We loaded it sequentially, front-to-back, always attempting to keep the current card, for the current day, in front, tossing aside yesterday's card when the day was over. This required a little training for my mother, but mostly she could handle this much.

Location

Another design decision was to find a location for this system within her apartment. The choice quickly became obvious. She has a 2'x2' table between her living room and kitchen on which sits her telephone, and often many of her notes and phone numbers. When anxiety strikes, she heads for the phone to call either me or my brother. This small table is sufficiently large to hold the rack of cards and the clock display, alongside her phone.

Deployment

Prior to leaving, I created all the cards needed for the duration of my trip, plus a few more. When my brother was able to visit (approximately every 3–5 days), he

could rearrange and repopulate the rack from the hidden stash of pre-made cards, or construct a new card himself, if necessary. Once in a while a card would get lost and he would have to recreate it. Other times, there was enough empty space left on a card for him to add something, like when he was planning a next-visit.

Aside. Specific to this period during my absence while traveling, and therefore not able to communicate with her, I thought it better to provide as much clarity as possible, to avoid any wild imaginations that could increase her anxiety.

In the past, her cognitive decline had induced moments of paranoia, especially in regards to abandonment: several times prior she had accused me of ‘being on a trip’ to leave her behind, never to return, even when no trip had happened. As such, when a real trip like this was in front of us, I wanted to make extra sure she understood I was going to return. So I felt this additional data was very important to have in front of her, constantly, while I was away.

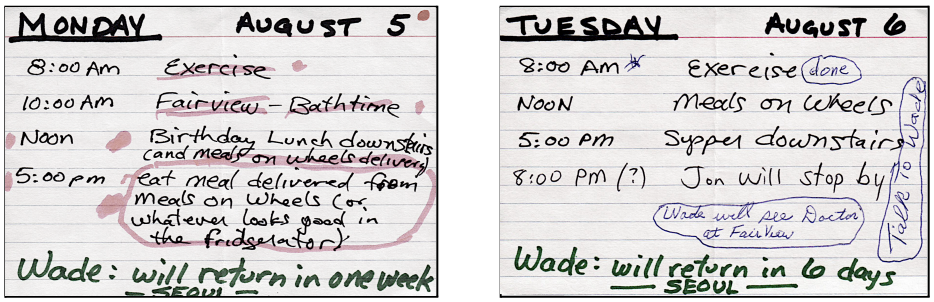

Figure 4. Example cards from Aug 5 and Aug 6.

To that end, I added a countdown, in the number of days, at the bottom of each card, offset by an alternate color (I chose green). Then, every day she could see, very clearly, “six days, five days, four …,” until my return. This information is consistent with the kinds of use-cases I considered for this system, as an *adjunct mind*.

Wrap It Up

All of this was setup and deployed in the days leading up to my departure, making minor adjustments to the cards until I had the desired, consistent format, as described above. There was not the luxury of time to develop this system much further. But early results hinted we were on the right track.

Since my brother would not be able to visit daily while I was gone, she was instructed on how to move on to the next card at the end of each day (or the next morning). Then my brother would show up every three or so days, and make any required adjustments.

After I returned from my trip, we ran with this system in-place for several more months, sans trip countdown messaging, shepherding it along on a quasi-weekly basis. The line items were typically about meals and visits, with an occasional event, such as the morning exercise class or a Saturday night film down in the party room. On rare occasions, my brother or I would add a comment about being busy, or working, or otherwise unavailable for the day.

There were not really any significant post-trip changes to the system. We were able to get several months of active use with it, which in my opinion is a pretty good run.

Focusing on one day at a time, rather than a full calendar, made a lot of sense. It was much less distractive, as we tried wall calendars from time to time, before. This was occasionally validated: I would call her, ask her “What’s on?” for the day, and she was able to read off the items on the list with relative ease. This was not possible for her with a wall calendar, not without a lot of prompting and potential dead ends.

The brass rack was already among her things. It was a familiar object, repurposed for this system. It had languished over on her desk with a bunch of forgotten letters and cards. Since it was a familiar object, it was comfortable.

Index cards were an inspiration based on the brass rack, combined with the idea of the one-day focus. As such, the first and most prominent piece of data on the card was the day of the week. Pairing this with the display clock further reinforced the focus on the current day. Although some days she forgot to change out the card, for a majority of days during this period she was able to achieve this on her own.

The format of the card was chosen to be of a familiar format: header and body, since so much existing material worked this way. Again, familiarity was the driving factor.

The location had to be where she would see it often, and since she so often sought to call us, it made the most sense to put this right by the telephone. This design choice had several advantages. One, when a need or anxiety struck, she would step over to the phone, and now be presented with a display of information that might just answer her concern. Two, when she did call, the conversation could steer her attention towards the display and reinforce the information being told to her.

OBSERVATIONS

This first prototype system was in-place and useful in her life for about four months total. Seeing how easily my mother took to this system was validation I was on the right track. The system was easy for her to use, as it was accessible for her use. As long as she could compare an index card to clock-display to ensure she has the right card for the day, she did fine. Sometimes, a quick phone call would provide enough assistance to move on to the next day's card. Other times, it had to wait until me or my brother could show up, to fix the arrangement.

She took to the cards very quickly, and I noticed the difference in her as she became more confident in her ability to use the cards. As a result, she became a little more autonomous, able to function 'on her own' with a noticeable reduction

in dependence on my brother and me for so many daily tasks. This system proved to be an obvious improvement over random notes and phone calls, and resulted in a noticeable reduction in her anxiety about what was going on. Later during this period, she grew a little too dependent on the cards, and began to value the cards as if they were some sort of higher authority.

While this system had many advantages over the daily verbal reminders and phone calls, it had obvious pitfalls as well. It was not without its problems. Although helpful, there were obvious challenges to keeping this system running. It required a certain vigilance on our part to continually make new cards, to make sure the information is correct and up-to-date, and to deploy the new set of cards on a timely frequency.

Although the cards helped her through the day, the time context on each card and each line item added a burden to her. She had to compare card information with the display clock for correct orientation. The requirement to do this was not always clear to her. Nor was she often good at knowing the day of the week.

The matter of which day?

Ideally, we tried to keep the ‘today card’ always front and center. I encouraged her to pull the ‘yesterday card’ the next morning, or optionally the evening before. But this was not always easily accomplished. This was one of the biggest challenges for my brother and me. To expect her to accurately track the current day-of-the-week was asking a lot. Although this was an anticipated challenge, mitigated somewhat by the proximity-placed full screen clock that boldly states day-of-the-week, there were many days where this did not work. Understandably, looking at one screen, remembering that piece of information, then looking at the card rack requires a certain level of functioning short-term memory, and not all days are equal when in the condition of cognitive decline. Still, having the card rack next to a full-screen display clock worked most of the time.

It was my intention, or hope, that she would be able to perform the ‘which day?’ question at the beginning of the day, and toss aside the old card from yesterday. Several times I had to instruct her on these procedures.

Mornings are usually better for dementia patients, afternoons and evenings being more affected by what is called sundowners syndrome in the elderly care industry. But even this is not always enough. Imagine yourself in these shoes, approaching this system in the morning. Maybe you are groggy, but in any case your mind is struggling a bit right now. You look, and the first card says it is Wednesday. But the clock says it is Thursday. Now there is a conflict, and your distracted mind goes in another direction, and nothing is yet resolved on the question of, Which day is it?

In the mind of someone with dementia, asking yourself, what day is it? is only one challenge. It is a bigger challenge to expect someone in decline to remember the answer, then keep this fact in mind, and finally search visually through the set of cards.

Flighty cards!

Another issue was the cards themselves were not affixed to their rack, and could be plucked away. In a sense, the index cards were too portable.

There were times when my brother or I would show up at the apartment and notice a random rearrangement of cards in the rack, often with previous days still on display. Or some cards would be fully removed from the rack, pulled and stored in her purse, or set down on an arbitrary flat surface. Some cards just went missing, without a trace.

Obviously we would have to refresh the rack to the proper order, remove the expired cards, and add new cards as available, or make them.

Interestingly, the tendency for pulling cards to stuff into her purse increased over time. This started happening about two months into the life of this prototype. (My mother carries her purse everywhere, that is where the valuables are!) This suggests these cards now had a value worthy of being put in the purse: the cards became ‘too dear’ and because of that they ended up in her purse! Afterwards they were of course forgotten.

Summary

The card-based system was mostly successful. At the time, I did not think to capture and compare metrics, like the number of phone calls, but this was not intended to be a quantitative study. But I can say this: we felt the difference. I was able to travel while my brother held down the fort. Her level of anxiety seemed much reduced, with exceptions for a few bad days now and then. Her increased self confidence was another huge benefit.

This system was sufficiently operational and effective for about four-months with only minor improvements. It was obviously beneficial to my mother during this period.

This system required ongoing management. Although the management of this system was easier to handle than before (mainly creating new cards), it also required vigilance and forethought to keep it running. It was easier because we could go up to five days without a desperate call from my mother, whereas before the calls were daily and back and forth. Thus it created more autonomy for her, and with it an increased sense of confidence that I could sometimes hear in her attitude.

Advantages:

- Can hold about a week's worth of reminders ahead of time on the rack.
- Supports additional 'future' cards to be held aside, making it easy to pre-make cards well in advance.
- With only a small amount of discipline the system can be self-sustaining for the week—the system is autonomous to some degree in not requiring anyone's daily attention.

Challenges:

- Which card? What is today?
- The cards can be lost, misplaced, put out of their intended order.
- This system still requires enough discipline from the dementia-afflicted person that might be asking too much, certain on someone's 'bad' days.

Notable results:

- Increased autonomy and in her level of confidence in herself.
- Reduced anxiety.
- Reduction in desperate phone calls (to me and my brother).
- Staff and residents in the building reported positive changes.

NEXT-STEPS & UPDATES TO THE BRIEF

Based on the experiences with this prototype, I envisioned many improvements. I could see little further progress to be made with a paper prototype. Honestly, though, I had in mind a digital version of this all along. Now it was time to take the next step to address the issues described above.

Although we experienced an increase in autonomy and automation, there was plenty of room for improvement: the system itself had to be more autonomous.

The next system would have to be fixed in-place, to remove the temptation to squirrel away the information of the day. Having a larger device would support the idea of its fixed location, as well as provide more opportunities for additional information or larger type size.

Finally, having more automation built-in, such as to switch days on its own without requiring our on-site intervention, would relieve us of the 3–5 day maintenance visits. And to relieve my mother of these same duties was equally if not more important.

New requirements:

- MUST not be so easily moved.
- SHOULD be larger to better support the idea of its fixed location (a larger display COULD also enable larger type and thus better legibility).
- MUST update itself to the current day and time.

Response Two: Going Digital

STATE OF THE WORLD AND WHAT CHANGED?

The index cards were recognized as a great improvement over the daily vigilance that was required before the cards. We were having a good run with the index cards, but there was mounting pressure to solve a few of its problems. Although there were only minor notable changes in my mother's cognitive decline at this point, the ongoing management of the system was becoming a bigger issue. Managing index cards was getting to be a huge burden for my brother and me. The only way to keep the system functioning was by in-person visits to our mother's place every 4–5 days. This was required in order to update the cards on the rack and address any other anomalies such as missing cards.

We probably would have continued with the index cards for several more months if it had not been for another disruptive event that would keep me from managing this system: I was diagnosed with cancer, the condition was urgent, and I was scheduled for surgery within weeks. The recovery period was expected to be a couple of months, and I expected to be completely out of commission during this time. There would be little or no opportunity for me to shepherd the index cards any further, and to dump all of the burden onto my brother was not practical.

What I learned from the index cards certainly helped inform the actions I took in the second prototype. In particular, I was drawn to solve two classes of issues: increased automation and having the system remain in a fixed location. This time, I knew it had to be something digital to achieve the automation. And because of my impending surgery, I had to move fast. I had about two weeks.

The digital world is vast and there were numerous ways to solve this problem. I had to go with what I knew well. I would leverage the kind of technologies I had been working with over the past several years: web-applications.

In this response, I first had to make several technical decisions: I defined specifications in order to narrow the field of options and to focus on creating a functional system in the time allowed. I then had to build up enough infrastructure to support the system, to become a pipeline from content management to display for my mother's consumption. Along the way, several visual design decisions had to be made, albeit in a quick and simple form, but justified for reasons that will be explained.

The remaining sections of the chapter are organized as follows. A technical description is given in section PART A. If you wish, PART A can be skipped without a disruption in flow, in which case you could move on to PART B. However, if you are inclined to skip, it is my recommendation that you at least skim PART A, in order to get a loose sense of this technical infrastructure, and how these components support the flow of content. PART B is the discussion about how content is managed and information displayed, and the rationale behind these design decisions. While PART B is central from a Design perspective, during this two week period, the bulk of the effort was spent in build the technical foundation, as described in PART A. Following this, the section OBSERVATIONS describes how the system functioned: what worked, what did not work so well, and other notable comments. Finally, the last section, SUMMARY, summarizes the updates to the Brief, and guides the chapters following this one.

PART A: BUILDING INFRASTRUCTURE

Technical specifications

As mentioned, I first had to narrow the field of technical possibilities as much as I could. I started by defining an initial set of technical specifications. These specifications look much like the requirements already in-play, only these criteria are directed to make technical decisions about the unseen parts of the system.

This portion of the system is akin to not having to think about the intricacies of the internal combustion engine, or in-car computer networks, or any number of technologies that comprise vehicle technology, in order to gas up and drive your car. However invisible these pieces are to the everyday user, they are no doubt essential. With the myriad choices available, and technologies to set up and configure, this is a hefty piece of work, and bounded by a set of initial technical decisions to be made.

Thus, the specifications are defined as follows:

- the system MUST have a display screen.
- the screen SHOULD allow for legible type, and be easy to read.
- the screen SHOULD always be on and available.
- the system MAY be constructed in such a way to look friendly and minimize its technology basis (such as hidden cables).
- the system MUST be data-driven.
- the data MUST be Internet-available (i.e., remotely-managed).
- the data MUST be easy to manage (i.e., for my brother and myself).

The first four specifications will be addressed in the section called Front-end. The sections Back-end and Connection will together address the remaining three technical specifications.

Technical decisions

The digital prototype system needed to be WiFi- and Internet-connected in order to satisfy the ‘data-driven’ and ‘remotely-managed’ specifications. As such, I forged ahead to find a device that would be the visible object in my mother’s apartment. The options for how to run the display were as follows:

- A computer monitor paired with a computer such as a Raspberry Pi, Mac Mini, or any number of other possibilities.
- A tablet, such as an iPad or any number of Android devices.

To drive other infrastructural choices there is the question of what software architecture to leverage. However, that is decided by the choice of using web-technologies. With that decision comes a front-end (client), a back-end (server), and a network in between.

Descriptions follow for the front-end, back-end, and connection pieces comprise the technical side of this iteration. This work addresses the technical specifications as laid out above.

It is common in software circles to refer to the client-side as the front-end, and I will continue to use these terms to mean the tablet and the web browser running on it. The server-side, or more often called the back-end, is where a lot of the under-the-hood logic takes place. I will use back-end to refer to these pieces that comprise the server-logic and the operating systems that support it. The back-end is used to serve-up content.

Here is how I will define these terms:

- **front-end**: technology used close to its user, typically visual presentation or display screens.
- **back-end**: the technology component behind-the-scenes and distinctly separated from the front-end, but often dealing with the handling of data.
- **connection**: the conduit between front- and back-ends that involves a stack of protocols, includes WiFi and Internet technologies; I will spend very little time discussing this piece.
- **content**: the data manifested and formatted in presentable manner; involves the concept of rendering, in my use of the term, and involves HTML as a means to achieve layout.

Although I include content in the list above, content will be a topic discussed in PART B. The front-end, back-end, and connection components comprise the infrastructural pieces that are discussed in this section.

The front-end

For the front-end, I wanted to keep the screen, as seen by my mother, as similar to the index cards as possible. This was for the sake of familiarity which I thought was an important criterion that was not specifically included in the brief or the modifications to the brief so far. However, I felt that in choosing the tablet, it was most like the index cards and in that way the friendliest of options. It did not have a desktop computer vibe about it, which I thought could be off-putting. Although I chose the tablet, I had no plans for touch-screen interactivity. It was all about how the device and its display looked.

Among the tablets available, the two main choices were between Apple and Android. I still had thoughts of eventually creating a native application for this system, and my familiarity with Android over my negative experiences with Apple development biased my choice. I chose Android.

I acquired a Samsung Tab A 10-inch display, a table-top stand, and third-party power cables with right-angle connectors, to hide as much as possible the cable going to the device. Eventually, this was setup next to her phone, in place of the index card system. The tablet-on-stand was only slightly larger than the rack of cards. This seemed to be a good digital replacement for index cards: physically not that much different in location and in size. I was reluctant to make any ‘big changes’ that required a steeper learning curve. This was to become the digital version of the index-card system.

The next step was to decide how to display the information and keep it on the display all the time. I had previously used Apple tablets (and Windows-based systems) as digital kiosks in a museum setting. Kiosk software with a built-in

web-browser was the typical arrangement when deployed in the museum, since it locked-down the device and confined it to a single function. I planned to do something similar with this system. However, within the Android ecosystem, I was unfamiliar with the dizzying array of Android (Google Play) kiosk app options. This led me to think none of the options were a quick solution, and now I was regretting my Android-over-Apple decision.

I decided to go forward with a standard web-browser, and then configure the device to be always-on. Since I was not too concerned about locking-down the device, I thought this was a good compromise, and a quick solution. But now I needed to figure out how to force the display to be always-on. As it turned out, the Samsung-implemented Android tablet made this more difficult, even with a constant supply of power from the wall. The device always wanted to shut off the screen after a certain period of time, and there appeared no standard system settings to stay on. However, after much digging I discovered a ‘developer mode’ setting that could achieve the always-on condition I sought, which worked imperfectly but adequately: it occasionally dimmed the screen, but it often immediately recovered to full brightness.

Without kiosk software, the browser’s address bar could be seen at the top. While all of this together was not ideal, I thought this configuration was close enough to get the job done in the short amount of time I had.

Bottom line, the tablet display was set up in her apartment, next to her phone, in place of the rack of index cards. And it was Internet-connected.

These choices, so far, satisfied the first four of the above specifications.

The back-end

As with the front-end choices, the back-end choices are perhaps equally vast. The available combinations of server-side frameworks, programming languages, and operating systems are too numerous to detail here. For the sake of brevity,

but at the risk of oversimplification, I will gloss over a lot of detail. Suffice it to say that the back-end consists of a ‘stack’ of technology: coded logic, often within a framework, that runs on the programming language’s run-time system, which is in turn propped by an operating system. All this runs on hardware of some sort, or to complicate matters further, virtualized ‘hardware’ that ultimately runs ‘on top of’ physical computer hardware.

The technology stack choices I used were all based on my familiarity with them. Simply put, I had to move as quickly as possible. I needed to code some logic, manage some data, and make that data available for the front-end. For that work, I chose the Ruby programming language. Ruby is a general purpose language, but is also a common choice for web-application development, especially with the popular Ruby on Rails web framework. I had much experience with Ruby on Rails, but it is an extremely robust and sophisticated framework, very much overkill for my current needs. So I opted for the lighter web framework called Sinatra. This allowed me to focus on the few pieces I needed to get done.

The Sinatra framework enables me to write an index.html file[3] which then gets rendered on the tablet display. Within the index.html’s header, I have specified a 30-second refresh, which is my crude way of performing ongoing periodic updates to the display. Thus, once the browser is aimed at the server, and has loaded the index.html, it waits 30-seconds, then automatically asks for the page again. The cycle repeats. Although it is a crude method, and not ideal, it is an effective way to implement ongoing requests.

The Sinatra templating system leveraging HTML is what drives the content and the organization of the content. These details will be discussed in PART B.

It is often the case to run Ruby-based applications on a Linux operating system, and I chose Ubuntu Linux for this purpose. I had an account with cloud-provider

[3] Technically, index.html is a template in the Sinatra framework, pulling in component templates as needed when building the HTML, on the fly, for the browser to display.

Amazon Web Services (AWS) and provisioned a virtual server (also known as AWS EC2) to run Ubuntu Linux. Next, I installed Ruby and other dependent software. With these pieces in-place, I then had a base on which to build the web application that could serve data to the front-end.[4]

Connecting it up

How the front- and back-end components were to connect was easier. The decision to leverage web-based technologies for this application already solved most of the communications problems. Internet access was no problem: my mother's apartment already had Internet connectivity and WiFi.

The AWS EC2 virtual machine I provisioned gave me a public IP address,[5] and the means to open it up to the world.[6] One last component was configuring and running the NGINX web-server software, to glue together IP addresses and web ports with the Sinatra framework.

[4] An AWS EC2 instance is a server-in-the-cloud, and acts pretty much like a physical server (computer) hooked up to a network. Running on the server is an operating system, in this case Ubuntu Linux. Linux is often what is used as a server-side technology base, and it's also what I'm familiar with. Once provisioned and dependent software installed, it is the platform on which to run applications and other server-side software, such as an NGINX web server. This server is accessed, mainly, in two ways: (a) SSH remote shell for me to edit files, and (b) via the web, to the web server, which is then routed to the application also running on the same virtual server.
[5] IP is Internet Protocol, which handles host-to-host packets of data. The next layer 'up' the protocol stack divides this into ports, which are then assigned to specific uses, such as web-traffic on ports 80 and 443.
[6] I did, however, restrict access to this so that only I could access its back-end plus a few rules to allow her tablet to use it. The AWS accounting provisioning tools made this easy to set up.

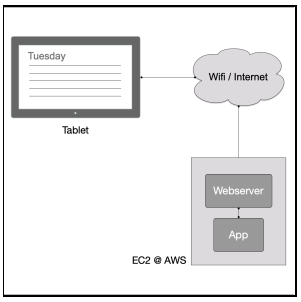

Figure 5. Tech stack diagram.

Finally, with all this plumbing in-place, I was ready to go from code to display.

The Linux server was available ‘in the cloud’ and I could access it remotely from anywhere I wanted via SSH.[7] This server contained the application logic (code), the content (data), and the web-server to deliver it up to the device in my mother’s apartment. Remote access allowed me to change the code, or change the content, as it was displayed on the tablet.

The data used to drive the display was managed by the code. As I was running out of implementation time, the ‘easy to manage content data’ piece fell somewhat short of what I had hoped to achieve. Nonetheless, it was easy enough for me to manage. So it was still on me to code and provide sufficient data for amount of time I would be fully-incapacitated. However, as I began to heal, I would be able to access this, and update it, remotely, from my laptop.

Thus, the final three specifications were met.

PART B: PROTOTYPE DESCRIPTION

The networking plumbing as described above was a fair amount of necessary work, but the goal was to build enough infrastructure, and then not have to worry

[7] SSH access is a computer-to-computer protocol for remote access. It’s entirely command-line stuff. Typically, on your laptop, you’d run a terminal program (macOS calls it Terminal, but there are other options, like iTerm). From the terminal side, on your laptop, you’d connect to the virtual server and it would be as if the server’s command line were in front of you. Then you type as needed. For this project, it was most often editing HTML template files.

about it. I wanted to get to the point where content would be created on ‘one end’ of the system, and then displayed for my mother. The more direct work was to decide what to put in front of my mother, how to organize the information, how to design it, and how to automate any changes we could.

However, as this infrastructure was put together quickly, the reality was a little different: some technology remained exposed, and as a result the management of the content required some degree of technical knowledge.[8] More significantly, I did not think placing significant technology burdens on my brother would work out. As such, this painted us into another corner—I was the sole person capable of updating the content. This put more pressure on automation, since I would not be around for a time to update it: the system had to contain enough to run by itself for at least a two- or three-week period, before I could get on to the server again to update it. Each week was mostly the same as the previous, with only a few exceptions at the beginning of the month. Since my absence was to start during the second week of the month, the system was good-to-go on its own for about three weeks as long as I kept the information generic enough.

The application logic is small, and it only responds to one type of request under normal operations. The logic captures day and time, then decides which day-of-the-week template to load, then the full page is built and sent to the tablet.

The displayed page layout was sectioned into two major parts which I will call the header and footer. But the application logic was organized by inner and outer HTML templates. The outer template remained constant and defined the main structure of the HTML page, including the header of what was displayed. The logic itself could insert day and time information into this template.

[8] In this case, knowing how to access and then knowing how to edit HTML. Access requires the esoteric knowledge about terminal software, command-line usage, remote shell SSH access, and Linux-specific knowledge to navigate its structure and edit some of the files on it. Editing HTML would require knowledge about HTML language and its structure.

The inner template was brought-in via an external file. The application logic determined which file by its internal logic, in this case by day-of-the-week. Thus the inner template files were named Sunday.html, Monday, html, etc., and contained only a few pieces of HTML, such as a DIV and other pieces to generate the list of information to be displayed. It was the inner template files that had to be updated when content changed.

The display layout

The page rendered was designed to be as simple as possible, to minimize confusion. I tried to mimic the index card, but now it could display the day-of-the-week dynamically, so there was less need to pair this with the display clock (we left the clock in-place as another reinforcing information source). This new, dynamic system also included the time of day.

The tablet was deployed just like the index card rack. At first, both systems were together, as a transitory step, but this was short-lived. The similarity of the tablet to the index cards was sufficient to easily replace it, and the cards could be completely removed from view.

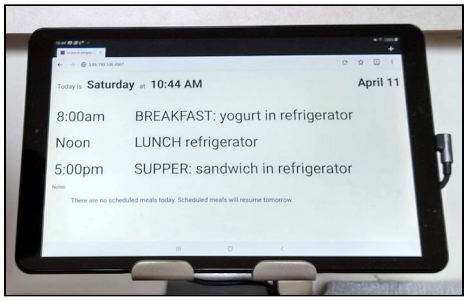

Figure 6. First deployment of the tablet-based system.

The choice of colors was also done to show similarity with the index cards, only I thought bright white was too bright for a light-emitting device, and so I wanted to dull that down a little. I thought I would use a warm color instead of grey since I thought that would be more attractive and attention-getting for her.

Initially, I also included a contextual “Today is …” in front of the day, but then later I eliminated this as it seemed to be unnecessary visual noise. Guided by the philosophy of familiarity, I thought there was plenty of precedent by having a calendar-like presentation say “Tuesday” instead of “Today is Tuesday.” Thus, I felt that would be easier to understand.

One last idea struck me, something I could easily do with this digital system: sleeping hours. Although this feature was not among the items listed to begin this iteration, once the digital system was in-place, I could see the potential for added helpful features based on its internal sense of time and automation capabilities. My mother had been losing a rational sense of time, would not sleep normal hours, and ended up trying to place calls to me or my brother in the middle of the night. The new system could define ‘sleeping hours’ and present a special template outside the days-of-the-week templates, to remind her that it is late and she should be sleeping. It was easy to set up. I defined 10:30 PM and 6:00 AM as sleeping hours and the message on the display for this period would be the sole message, “you should be sleeping now.”

Wrap It Up

I had all this working and in-place in her apartment just days before I was scheduled for surgery. The messages were good for a week, then repeated, and I had not set up any mechanism for my brother to care for this information, and there was nobody else enabled to update it. As such, I kept the day-to-day information as generic as I could. She had an irregular meal schedule from one day to the next, but fairly consistent from one week to the next. I felt this system could be workable for several weeks, so I had little worry about it. If there were any exceptions, my brother could handle it with a phone call or just show up.

Once I recovered enough to continue ongoing updates remotely, I could make any necessary changes as we used the system and got more used to it. This instance of the system was in-use for a couple of months before we moved on to

Iteration Three, which is to say we made a few changes to the same digital system. The differences between Iterations Two and Three are much more incremental, improvements on the same theme. As such, many of the successes in this iteration apply equivalently to Iteration Three.

OBSERVATIONS

From an automation perspective, this system was a huge success over its predecessor. My brother and I could just ‘let it run’ and have the automation do most of the work. It reduced the burden for us, as was its goal.

From our mother’s perspective, however, it was pretty much the same messaging, which is good. The fact that it was a bit of technology turned it into a novelty, and that was also a positive experience.

We addressed the fixed-location problem: she couldn't take it with her. This was both good and bad. On the good side, it did not go missing like many of the index cards. On the bad side, however, there seemed to be a reduced perception of value. In my opinion, since she could not hold it in her hands, or take it with her, in her purse, this system was somehow more ‘outside’ of her and as such had less perceived value to her. Her sense of ownership was greater with the cards because they were more tactile. I think this was generally a small effect in the long run. Even though she felt more neutral towards it in the beginning, she grew to rely on it. Over time, this system became a sort-of anonymous authority over her life, and that was comforting enough.

The period during my medical absence went well. Ongoing, the system functioned well for the goals I set for it.

As our experience with this system advanced, we learned how it was effective and also when it came up short. One glaring omission was that we had never named it. As a nameless device, we would refer to it as ‘device’ or ‘screen’ or any

number of generic references. This turned out to burden the communication about the device. It really needed a name that she could connect with, a name that we could all use. Having a name for this device became necessary in order to talk about it or draw attention to it, such as while we were on the phone with my mother. My saying “look at the screen?” or asking “what does it say on the device?” would often be misunderstood or confused. After all, there were other screens and devices among the artifacts in her apartment. It was also a little cumbersome to talk about this nameless device with my brother. It just needed a name, something catchy. And nothing too strange, as perceived by her.

I have already mentioned how quickly and crudely I put this system together. Because of the way I chose to perform refreshes (every 30 seconds), the device was vulnerable to connectivity interruptions with the WiFi or other Internet outages. Even relatively short glitches, timed right, could suddenly render the device inoperable. It was fortunate the device kept working without a hitch over the first month and a half. But once these outages started, they occurred with unpredictable frequency. The work-around is simple: you perform a browser refresh, but this was not something I could have my mother perform, even if I guided her through it.

Another emerging behavior was my mother’s increasing inability to recognize which line items were in the past, and which ones were still relevant. This is similar to “What day is it?” question, discussed in the previous chapter. Now we are at “What time is it?” while looking at the items among the list. For example, let’s say she would call me at 4:00PM, worried about food. I would ask her to look at the device (again the name problem) in order to see that supper was scheduled for 5:00PM. But instead of looking ahead to the next item, she would read off item by item from the beginning of the day, starting at 8AM.

Finally, a growing and nagging concern was the content management of the system: it remained in my camp but I really wanted to delegate this to others.

Summary

As with the index cards, my mother took to the new digital system and learned to use it and depend on it. The system worked well for us, it was an effective tool. From the time it was initially built to when I made another round of changes was several months: another successful run!

As hinted at above, my mother began to trust this system as some sort of ‘outside’ authority. She did not really understand where these messages were coming from, that these were the results of my editing the content, and she would often point out aspects of it to me when I was with her, as if I had not seen it. It appeared she was losing her concept of cause-and-effect.

In the end, however, it was effective in getting her to understand when her meals were coming, when other in-home service people were coming, and when other events were occurring. She loved movie nights, and was quick to call and tell me about it when it showed up on the display.

Advantages:

- Focus: presents only the current day’s worth of information.
- Automation: we could let this device run for longer periods of time after a week’s worth of remote setup, and adjust and update as we saw fit.
- Greatly reduced our burden as caregivers, while at the same time remained as effective as the index card-based system, if not even a little improvement.
- Affords us the ability to provide special, time sensitive messaging, such as “you should be in bed” during the nighttime hours.
- Fixed to the location where we put it. It was much harder to disappear.

Challenges:

- Naming: we did not know what to call the device, and that made talking about it more difficult.
- Complexity, it requires more digital infrastructure: content management, additional technical complexity, information privacy is at greater risk.
- Susceptible to WiFi or Internet outages.
- The line-items lacked a current-time context. There was no strikethrough or gray-out of past information, or any other indicators to show which line item was next.
- Device-specific quirks (although minor, in practice):
    - Occasionally, the screen goes dark;
    - Elimination of visible distractions (e.g., browser address bar);
    - Always-on, tethered to an outlet, and requires a stand.

Notable results:

- Focus on the current day meant no more lost cards. The system was always on the right day (barring other occasional technical problems).
- Greatly reduced caretaker management for my brother and me allowed us to get to the next stage, and got us through my recovery period.
- Special messaging guided her behavior to be more reasonable (there were less late night calls to my brother and me).
- More dynamic: can react to new information more quickly.

NEXT-STEPS & UPDATES TO THE BRIEF

The index card system was an instrumental prototype that informed how this first digital system was designed. We were able to ride on previous successes while developing the digital version, keeping what worked. The shortcomings of the

index card system were the gems with which I could drive the new features of the digital system. Likewise, the shortcomings of this digital system will drive the next iterations.

Although not manifested in the application or in the digital world in any form, the highest priority next-step was to give this system a name. We could not use any arbitrary name because it had to resonate with my mother's ability to recognize it. We could not make the name too generic, either, because then it would be too easily confused with other objects.

As for use of the system, we would occasionally notice that our mother would not have a strong sense of the current time, and as such, she would not immediately recognize the significance of a line item. Most of the time she did well enough, and it was not a big deal. Later, it would become a much bigger factor, but at the time we did not know it yet.

Also during this period we noticed how some messaging worked better than others. Basically, the simplest way to express something was often best.

Operationally, the system was a little unreliable. It could go for a month without a glitch, but it could also experience back-to-back days of glitch-caused outages. This resulted in a bigger burden for my brother and me, in resetting the device when that happened. Interestingly, we would usually get a call about it when it did fail. That told us our mother was pretty constantly relying on the information, and when it went out, we would get a call. Fixing it was a simple browser refresh.

Finally, keeping the information up-to-date was a task in itself, however, nothing like the amount of effort the index card system required. It was an advantage that I could pull out my laptop at any time and just about anywhere, and update or fix some content. But what I really wanted to do was to delegate some of this work, and that would require more of a usable content management system, and out of the realm of editing HTML.

New requirements to be added to the Brief:

- MUST give it a name suitable for all parties, patients and caregivers.
- SHOULD indicate which line-items are past, which are upcoming.
- SHOULD improve reliability, resiliency against glitchy connections.
- SHOULD improve content management of the back-end systems.

Response Three: Experiments

STATE OF THE WORLD AND WHAT CHANGED?

I have observed how isolation is a huge factor in the acceleration of dementia, and, conversely, how socialization counteracts the effects of dementia. My mother's move in 2017 from remote northern Wisconsin to a senior independent-living apartment complex in south Minneapolis, near us, was a huge help to her. Not only were we able to check on her frequently, she made many friends at the building. The social time with other people was invaluable. The friends and activities in the build really supported her, and slowed her cognitive decline. She endured well for two years after she moved in.

The COVID-19 lockdown changed everything. My mother did not know what a pandemic was. She did not understand the reasons why we had to wear masks and reduce interaction with each other, but she knew enough to comply with these new rules. New building policies, and a generous amount of fear among the residents of her building, had a chilling effect on social interaction. There were no more gatherings of any size, no movie nights, no games, and no outdoor patio barbeque parties. Even simple things disappeared. Visiting together with coffee vanished. It was rare to find people sitting together, talking. Family visits were reduced, too. Policy stated only one family member should be the designated visitor, but it did not take long before staff realized in our case we needed more, and then both my brother and myself were allowed to visit.

As a result, my mother spent the majority of her time alone in her apartment. Meals were delivered to her door and she ate alone. Home health aides were allowed in. They showed up at her door, too, but they would be strangers to her. At least she was getting some regular visits by this. She did not get out much on

her own. My brother and I would visit as often as we could, but that was not always so easy either. She would see one of us every 3–5 days.

This was a profoundly isolating experience for her, with a concomitant devastating effect. My mother's cognitive decline accelerated during this period, from March 2020, when the lockdown began, until late October, when she was ultimately moved into memory care, a seven month period.

During the months between March and August we endeavored to maintain a sufficient level of caregiving, but her needs kept on growing. At the start, there was my brother and I, and one hired professional. The hired aid helped my mother with her bathing and light housekeeping.

By August, and continuing through October, I was managing a group of hired caregivers. We were scrambling during these later months until she moved into memory care. We stepped up in-home care services, employing two service provider companies. Sometimes my mother was getting visits more than five times per week just from the professionals.

Also during this time we began the search for her next living arrangement, memory care. By this time, it was clear to me she needed around-the-clock care. The reminders system was no longer providing sufficient support. But until we found a new place for her, we had to do the best we could with the tools we had: the reminders system, the hired professionals, and our own efforts. My brother and I made more frequent calls and trips to her place. And the reminders system still helped fill-in some of the gaps.

My mother’s cognitive decline moved quickly during this period, although its scale is easier seen in hindsight. It was evident her language skills were declining to the point where she sometimes made no sense. Her ability to understand concepts was waning, too. I got somewhat used to it, and I could guess what she was saying most of the time. The reduction in vocabulary, in particular nouns,

seemed pretty dramatic to me. Her common speech was now absent so many nouns, these were replaced by pronouns like “it”, “this”,“that”, “thing”, “she”, “them”, “her”, etc. However, she could recognize many of the missing nouns if I spoke them to her. Her pronouns were equally challenged. She could not remember anybody’s name, only the closest family, and sometimes only my brother and me. Verbs seemed to hold on better, for some reason.

The conversational guessing game got me curious. Although I was not meticulous about documenting her use of words at the time, I kept a mental track of the more common words I knew she would understand. Of course, over time, her vocabulary got worse. My mother’s understanding of concepts got worse, too. It became more and more challenging to communicate with her through written text (i.e., on the reminders system).

In addition to declining language skills, she was also losing her sense of time. Recall, in chapter Response One, I discussed her difficulty in knowing the day of the week. That was a year before. During this period, it was evident she was also losing her sense of the time of day. This time-of-day disorientation manifested all sorts of disruption to her normal schedule. She was up at night, sometimes attempting phone calls. And she would sleep in her living room chair at random intervals, day or night. As such, working with the reminders system increasingly became more of a challenge.

Of course, back in March, I did not foresee this picture. I was happy to forge ahead with what I knew about improving upon the existing reminders platform as much as I could. After all, this system was performing adequately at that time, and although rebuilding it was something I still wanted to do, I was not ready to embark on that level of work.[9] As such, this chapter is about the changes and experiments I made during this seven-month period.

[9] Actually, I badly want to remake it. All the time I had thoughts about fixing this or improving that. But I simply did not have any bandwidth to take on this additional work.

RESPONSE DESCRIPTION

Name: what to call it?

The most obvious and ongoing shortcoming at this point was naming the system. The importance of this goes well beyond marketing or branding. It was not about that. The basic need was to be able to communicate about the system between my mother, my brother, and me. Without a name, it was cumbersome, at best, to have a conversation about it. Furthermore, while I might be able to get a well-functioning person to recognize the reminders system by description, it was extremely challenging to do this for my mother. I imagine it would be the same challenge for anyone in cognitive decline.

For example, I would be on the phone with my mother, saying to her, “look at the device,” or, “look at the screen,” in all sorts of attempts to bring her attention to its display. These too-general phrases would often fall flat. These words were easily confused with other nearby objects: display clocks, a bulletin board, a wall calendar, the desk phone, etc.

There needed to be a direct way for either my brother or me to refer to this device, as unambiguously as possible. Yet, the name should not be too abstract either, otherwise our mother would confuse or forget that too. For a normally-functioning person, any catchy, unique name would suffice. I could call it RemLux or XO-mind or any number of unique names, but I was certain those would not resonate with her. I doubt they would work with anyone with cognitive decline. I speculate, if a name like this was already established from a time before cognitive decline, would it then remain familiar during the decline?

The bottom line was: the name needed to be familiar to her, yet discriminating. The range of possibilities was narrow because of her reduced short-term memory function and declining vocabulary. As such, naming this device was a struggle. I tried several familiar words, such as the following:

- “device” — I used this early on, but it was obviously too generic.
- “screen” — Also too generic.
- “reminder screen” — A little clumsy, and tended to be confused with other screens in the room, such as the display clock.
- “reminder buddy” or just “buddy” — This one was cute and it seemed to work some of the time, but it was quirky enough to fail occasionally as well. It was deemed unreliable.

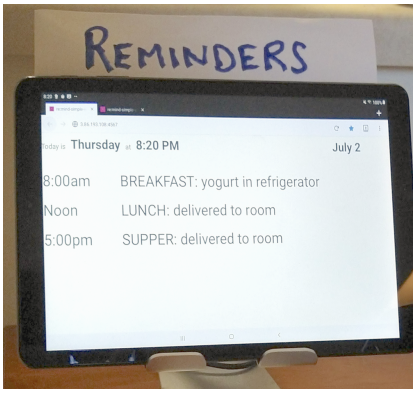

Figure 7. Reinforce its name with cardboard backing.

Finally, I landed on ‘Reminders’ as its name, but I felt it needed reinforcement. I wanted to have the name always presented, like it was a part of the screen. As such, I quickly created a prototype from light cardboard stock that I found in her apartment: packaging material that came with a printed calendar. I put the cardboard along the back of the table, extending about 1.5–2.0 inches above the top edge of the screen. On this, I quickly scrawled ‘Reminders’ with bold san serif lettering, and folded it to fit behind the tablet. Then, I introduced the name to her, to see what she thought, and how well she might attune to it. There was a glimmer of hope in this result, so I left it in-place to see how it would do over time. And, over time, it worked better than any of the other options.

Connection resiliency

The 30-second refresh loop[10] inherent in this implementation exposed this system to potential outages: it is sensitive to Internet connectivity glitches. The problem occurs in this way: when Reminders needs to refresh, which is done frequently, it requires a stable Internet connection to the server. It only takes one brief glitch during a request attempt to render the display useless. Once this has occurred, it will not attempt any further requests.

Doing the math, Reminders makes 172,800 requests each day. If any one of those fails, the application is down until it can be manually restarted. My mother's Internet connection is pretty good, but not perfect. It suffices to say it fails often enough to be a once-in-a-while problem. On average, this occurred about once every four weeks. That's five million requests!

When Reminders fails, the browser's default error page is presented instead of the usual information. Often, when my mother saw the error page, she would call me or my brother. She did not understand the error it displayed, but she knew enough to report the problem to us.

Fixing Reminders to automatically re-trying requests required rewriting the application, a big task. The only method we immediately had to address this issue was to have someone tap the browser refresh button. It was easy to fix, but it was not easy to explain this to my mother over the phone. On rare occasions I was able to talk her through it, but usually one of us had to make the trip to reset Reminders. Since I lived only 10 minutes away from her, it was often my task.

Frequently, other caregivers were in her apartment, aides to assist her with bathing and light housekeeping. These providers were also given instructions on

[10] The refresh occurs every 30 seconds via a browser-directive (meta-tag) in the header of the page. Once a page is loaded and rendered, the timer counts down for 30 seconds. Once the timer is done, the browser attempts, only once, to reload the page. If successful, the process repeats, thus creating an ongoing refresh. However, if it's unsuccessful, it stops. If the request fails, a default error page is presented and the process entirely stops. There are no retries.

how to reset Reminders. That was the work-around. Between us and the hired caregivers, performing the browser resets, it was the best we could do without having to fully rewrite the application.

Line-item focus

At this point, Reminders listed items linearly and with equal emphasis. There were no special treatments for past, present or future, or for any other reason. Everything was the same font, weight, emphasis, and color. Before this point, I would sometimes manually edit the HTML on the back-end to highlight holidays or other special events with brighter colors. But I had not made this a regular practice yet.

During this period, I created CSS styles to gray-out and strikethrough text. I then used these styles to expunge past events, but this was all done manually, in real time, editing HTML sometimes several times in a day, to make it appear real-time. It was an arduous task for me to keep this up.

Given the current implementation of Reminders, there was not an easy way to automate this task. As such, I would make these changes manually, ongoing. But it was not practical to keep this up, as much as I tried. The results were somewhat random updates, whenever I would remember to do them. To really do this right, manually, it would have required me to vigilantly edit the back-end several times per day, every day. This, again, was becoming a huge burden. Again, I had a work-around to ‘solve’ a problem without really solving the problem.

Scrolling. With the increased level of service provider visits, some days the Reminders display got a very full mix of meals and visits. On these days, I was concerned it was displaying too much information at once, and that would be too much for my mother to visually parse. I wanted to avoid scrolling. The choices were to either let it scroll, reduce the font size until it fit, or reduce the amount of

information displayed. I chose the latter. I wanted to avoid scrolling because I didn't want to force interaction. And, as mentioned before, it is good to reduce the visual clutter.

As of yet, I had no automated way of scrolling or focusing the display to the time-relevant portion of the day. When days did fill-up or go beyond the bounds of the display frame, I took special measures to hand-edit that day's events to fit the screen. If it was morning, I would hide events from the end of the day. As the day wore on, I would edit again to unhide these later events, and in turn remove the earliest expired events of the morning. I would always eyeball it to keep the display relatively uncluttered. Since I was already manually updating content to indicate past events (as mentioned above, with strikethrough and gray-out), I might as well edit for this case too. This also required my attention several times throughout the day.

Content experiments

I experimented with language, imagery, and icons. These experiments started with language as the core method of communication used by Reminders. Because my mother's language skills were declining, I also started experimenting with other visual forms of representation. I was hoping to better understand what benefits these treatments could provide. I used icons, photographic images, and text-treatments, such as colorization.

Language. In the beginning, I knew enough to keep the language as simple as possible, but I did not put much further thought into it until this stage. Now, I kept constant focus on the wording of each line-item. These had to be kept dramatically simple. During the pandemic, there were only two classes of activities: meals and visits. For meals, I would always prefix these line-items, in all-caps, as "BREAKFAST", "LUNCH", and "SUPPER", followed by a very short phrase about how she should get her meal. There were really only three ways for her to get meals: some were prepared and made available in her refrigerator,

some were cooked elsewhere and then delivered to her room, or they were cooked in her apartment by a visiting caregiver.

Typically, she was on her own for breakfast, and we had to prepare these ahead of time. These were often prepared by my brother, labeled, and placed in the refrigerator. Breakfasts were usually a yogurt cup with something nutritious mixed-in, like nuts or berries. When it was breakfast time, the line-item on Reminders would always be the same. It would simply say, “BREAKFAST: yogurt in refrigerator.”

Weekday lunches were, “LUNCH: delivered to room.” Suppers were a little more variable, as were weekend meals. That’s when the hired staff filled-in. The line item in this case would display something like , “SUPPER: Marcy will help.” Note, however, this mixes a visit with a meal, and raises another question. Which idea takes precedence? Do I call it a visit (and she also gets a meal), or do I call it a meal (as a result of a visit)? Since she was more food-focused at this time in her life, I tended to say it was a meal instead of a visit, with no further elaboration.

Visits, of course, were the other class of line-items. These, like meals, went through a series of experiments, but I quickly arrived at a simple prefix/name format; for example, “VISIT: Wade”. This format was used for everyone, hired staff included. However, as mentioned above, when that person was also preparing the meal, the line-item focused on just the meal and not the visit.

Icons. I experimented with icons to further distinguish between the two classes of events, highlighting meals while leaving visits alone. I found an existing icon depicting a bowl of hot food, and included it within the prefix for each meal line-item. This icon, of course, was removed once the line-item expired and was otherwise grayed-out. It was only meant to catch her attention for meals that were about to happen.

Color. Not to entirely ignore visits, I would sometimes highlight a visit with color, especially if it was me or my brother visiting, or if it was an important appointment, such as a doctor or nurse. These were the visits she cared more about, the others being more routine.

Images. During the latter months of this period my mother was not looking at Reminders as much as she needed to be. As an attention-getter, I started putting images at the bottom of the display in blank area of the screen. I tried old family photos, pictures of animals (both pets and wild), and landscapes. I thought the landscapes would be soothing to her.

OBSERVATIONS

Name. As it turned out, something as simple as giving this system a name was an important achievement. Once I named the system and reinforced it with the cardboard backing, she took to the name well. The backing was an essential piece. Without this reinforcement of the name, her association of ‘Reminders’ to this device would obviously wane, while having its name written boldly next to it, always visible, was an effective and ongoing reinforcement of its new name. Also, with this name, my brother and I were able to easily talk about it amongst ourselves. Especially important, was that I could converse with my mother on the phone and ask, “What does Reminders say?” and she would know what to look at. This was a big difference.

Connection. There is not a lot more I can say about the intermittent connectivity issue. It was an ongoing problem, but we had a work-around, annoying as it was to deal with. She was usually quick to call one of us when an outage happened, simply because she could not understand the error-screen Reminders displayed.

Line items. My mother’s time-of-day disorientation manifested in not knowing which line-item was more important than another. She could no longer discern what item was current. It was a growing concern to me that she constantly

required help with this. She was obviously getting more disoriented during the latter months of this period.

For example, I would call her at about 4 PM, an hour before supper. She would tell me there was not any food. I would respond, “look at Reminders,” and she would respond by reading down from the very top item: 8 AM breakfast, 9 AM visit, Noon lunch, etc., with little apparent distinction between events. The behavior was always to start at the top, traversing down the list. In these conversations, I would then point out that supper is less than an hour away, and it will be delivered to her door. Then she would be relieved, but it was no longer Reminders putting her at ease.

A way to focus her attention among the line-items was becoming an essential feature in order for her to interpret the information in a usable way. The applied text styling, although done manually, worked really well. She was able to track the relevant items on the display. It made a huge difference for her when I was able to perform the manual formatting changes. The phone conversations at 4PM would now go more as expected: she easily found the current item. These styling differences were sufficient for her to mentally skip expired line-items.

I was highly motivated to keep making these manual updates, as burdensome as these were to me, because the results were so effective. But, although it made a huge difference, I could not really sustain this activity, either. I urgently had to find another way.

Scrolling. When I set out with this project, my intention was to not require my mother to interact with Reminders. It was to be a display-only device. Scrolling would violate that condition. Another, related goal was the reduction in visual clutter. Some days were simply too busy, too full of activity. As such, I was forced to accommodate this need, albeit by manual edits. I have no hard evidence or clear observation from her activities that this reduction in display clutter and

avoidance of scrolling helped her, but my intuitive sense tells me the display had to be visually clean.

Content: language. With my mother's ever-decreasing vocabulary and reduction in understanding concepts, it was important to keep the language very brief, and always concrete. Word choice became an ever-increasing challenge. Eventually, even the word "delivered" became a stumbling block, and I had to replace it with "brought." After that, I reduced it further to, "in your room." And during her final days at the apartment, she occasionally became confused by "in your room," because then she would then look for the meal in her room, not realizing the meaning was 'yet to be delivered to her room.'

Her condition, indirectly, reminded me of the book *Thing Explainer*, by Randall Munroe (2015). In the book the author challenges himself to explain fairly advanced technical and scientific concepts using only the 1,000 most commonly used words in the English language. While thinking about my mother's reduced vocabulary, I would often think about this book, and wonder where she was at, and at times it seemed lower than a 1,000-word vocabulary. I also realize there is a big difference between coming up with words when speaking and recognizing words when other people say them. But I also wondered how I could have captured a picture of her vocabulary-level at each stage of her decline, by some metric like vocabulary count.

Content: icons. I added the food icon to help distinguish meal times from visits. In emphasizing meals over visits with icons, I wanted the simplest possible icon that I could find, but one that would still resonate with her idea of eating. She often had bowls of soup, so this became the best food icon. There was no clear feedback on this effort, but intuitively I thought it helped, and so I kept including icons with food-related events.

Content: images. Finally, the images I added were met with mixed results. The motivation was to grab her waning attention, to look at Reminders. The results

were usually complaints and questions. First, I tried using old family photos, and that seemed to work for a while. Sometimes, it would be a photo of someone who had passed away, and that would make her upset. Most of the animal pictures were met with rejection. She would ask me, “Why is that monkey there?” Then, I tried innocuous animal pictures, but even with cats and dogs, she did not understand why the animal was there. Lastly, I thought landscapes potentially seemed the most neutral. But, again, she did not understand why these pictures were there. I decided images were too complex to figure out, and abandoned the idea of these as attention-getters. I concluded that images were distracting her from the real messaging.

NEXT-STEPS & UPDATES TO THE BRIEF

Name. The name Reminders was arrived at quickly for practical reasons. It worked in our case, but when considering how to generalize this to a larger audience, I am not sure it is the best name. More research is required. Possibly, the name for any given deployment might have to be a configurable parameter, probably separate from a marketing name (if this system should ever reach that level of status).

Connection. Connection resiliency is obviously very important. We cannot have frequent failures, and we do not want any failures showing up on the screen. The work-around was barely adequate. This needed to be automated.

Line item focus. Like the case of manual mitigation for connection failures, frequent and ongoing updates to the content, to simulate real-time, is also not sustainable. Again, the work-around is barely adequate. These updates need to be automated in real-time, so they are always accurate and up-to-date, thereby reducing potential confusion.

Scrolling. The reduction of visual clutter on busy days is going to be an ongoing challenge. Busy days happen. As a side note, this raises a topic: Why continue to

show expired events when they could simply disappear? It is a good question, worth exploring beyond this case. While the elimination of early events once expired would solve part of the problem—when displaying events at the end of the day—it would however not address the clutter that would exist at the beginning of the day. Something else has to be done.

Why show expired events at all? Recall, the main driving concept behind Reminders is the *adjunct mind*. Keeping expired events around in some form is a way of reminding someone, ‘Look at these things you have already done,’ much like seeing checked-off boxes on a to-do list.

It is also important to distinguish between past, present, and future. As such, I have been considering a new user-interface, one that keeps enough information around, but centers on the present. In this proposed user-interface, past items would fade away to a degree proportional to the amount of time passed. Said another way, only recently-past items would be displayed at all, although de-emphasized in preference to the current item. Likewise, future items would have a similar treatment: only near-future items would be displayed. As time marches onwards, each next-future event is brought into the fold.

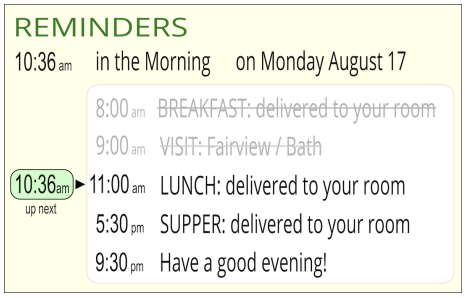

Figure 8. Proposed design for next phase. Work in progress.

At the very minimum, such as user-interface would only display three items: (a) the next-previous item, with de-emphasized text treatment, (b) the current or upcoming item, with the greatest emphasis, and (c) the next-future event, with some sort of neutral text treatment to allow emphasis on the current event, but

not to confuse it with the past one. This would reduce visual clutter while guiding attention to the most relevant item. Another approach could fade-in and fade-out more gradually, as suggesting there are more items in the past or future. This is an exciting new area I hope to explore.

Content: language. A careful focus on simple and direct language is always at the forefront for communication to cognitively-declined people. Determining appropriate vocabulary is an ongoing task, in proportion with the decline of the individual being served. These things are to be closely monitored, and as of yet I have little advice about how to make this task easier for those of us who need to communicate messages to this population.

Content: icons. I think icons can be useful, ongoing. As with word-selection, these ideograms need to remain as simple as possible. As for how to determine this, more research will be necessary.

Content: imagery. Experimenting with images unsurprisingly showed me that unfocused content has no place in an application like this. I thought it could provide a little fun, but it did not even do that. It is about keeping the display as simple as possible, and avoiding irrelevant content.

The food icons seemed to help reinforce line-items for meals, although more research will be required to validate that idea. Along similar lines, I arrived at the idea of having a headshot and name of each person that was visiting that day somewhere on the display. These could be small, icon-like images included with the line-item text, or they could be separate on the bottom of the screen, in the open space. This would have at least two advantages. One, names are easily forgotten, so this would reinforce the name with the face, especially for hired professional help that might otherwise be unfamiliar to the patient. Secondly, if the visitor is indeed new to the patient, seemingly a stranger, then this serves to reinforce that is not any stranger, but is someone who is supposed to be there.

New requirements to be added to the Brief:

- SHOULD review its name, making it suitable for general use.
- MUST address the connection/resiliency problem in a way that does not require human intervention.
- MUST emphasize most relevant line-items for the given moment, or de-emphasize least relevant items.
- SHOULD reasonably accommodate the case when the number of line-items for a given day exceeds the display capacity, or even the visual capacity of the viewer when considering the reduction of visual noise.
- SHOULD perform more research into language selection, how to determine an appropriate and reduced vocabulary; also, this research SHOULD consider how the vocabulary will vary by individual.

Response Four: Single-Page App

STATE OF THE WORLD AND WHAT CHANGED?

The period of time during COVID-19 lockdown had a profound impact on my mother. From its beginning, c. March 2020, until her move into memory care, in October, was about seven months. The acute effects of this lockdown period, documented in the previous chapter, indelibly altered the course of her life, and is an important aspect to this fourth iteration of Reminders.

Due to social restrictions and her building's policies put in-place because of the pandemic, my mother experienced an extreme sense of isolation. Before the pandemic lockdown she was 'fed' by the social interactions she had with friends. The withdrawal of this interactive culture removed this pillar of support for her, and with that, her cognitive abilities dramatically declined. It was at this point, we came to realize that we could no longer keep up with her needs. She needed 24-hour care. She needed to be moved into a memory care facility.

Finding a facility and making arrangements took a couple of months, and, in the end, we moved my mother into her new studio apartment in memory care in late October. The similar size and layout was intentionally created to replicate her old apartment, to make it seem more familiar, and to ease the transition. The square table used as the phone-table was set up the same as before. On it, we arranged her phone, the display clock, and the Reminders tablet, as they were arranged before.

As documented in the previous chapter, Reminders needed several changes. However, now that she lived in memory care, with around-the-clock services, it was not clear how the changes in her living arrangements would alter the requirements for the device, but I did not let this alter my trajectory. In the spirit of forging ahead, I made the needed changes, as they were documented.

I did not yet foresee the dramatic shift in her needs, and how these efforts could have been adjusted to better accommodate her in the new environment. These results, and the realizations and observations that followed, are documented in the section OBSERVATIONS in this chapter. This will be the final iteration documented in this thesis, but not in the overall plans to continue with this project. As such, in order to maintain a similar flow to this chapter, the NEXT-STEPS section will expand on what could have been done in a fifth iteration, if there had been one. As for the additional changes and features beyond an imaginary fifth iteration, I will elaborate on this topic in a separate chapter called FUTURE.

This chapter focuses on the changes I made to Reminders c. October 2020, the deployment of these changes into my mother's new environment, and the experiences I observed subsequently. As such, these observations represent the period from October 2020 to March 2021, about a five month duration.

First, I describe the technical changes I made to Reminders. Then I follow with the content changes which were driven by a completely new set of needs as a result of having moved into the memory care facility.

RESPONSE, PART A: REBUILDING APPLICATION

For this iteration I set out to rebuild the application using a new approach. The architecture used is called a Single-Page Application.[11] This pithy phrase expresses two salient concepts. First, it uses a single-page. This is another way of saying it requires only a single-load (from server to browser) in order to

[11] Single-page application (SPA). Before jumping into the front-end work, I have a few words to say about how javascript-based front-end applications work, and a comparison between the old and new ways. In either approach, you have a browser on the front-end and a server on the back, serving content as a result of requests made by the front-end. In SPAs, the initial request is done manually: e.g., a person goes to a website address. The response is to load the application code from the server, into the browser's javascript runtime system. Once this application begins to run, the application itself requests the next piece, in the form of data. Once the data is loaded, the application renders the page based on a combination of data and internal parameters. But the application doesn't stop there. It can continue to run any logic that it's been coded to do.

perform all its functions. Secondly, it is an application, and not just a webpage. The initial load brings all the coded functionality into the browser's Javascript run-time system, then it begins executing the logic and rendering the content. It is the code in the browser that determines what content to present, and how to present it, and when to change it. The distinction for Reminders is that this new implementation runs entirely in the browser, on the tablet, and not on the back-end server as it was doing previously.

When I first set out to build the initial digital Reminders system, I began with a set of technical decisions. Those are described in chapter Response Two. This iteration is no different: I am faced with a myriad set of choices in order to make an SPA. As before, this software development effort begins with defining a set of technical specifications and options to consider, and some guiding principles used to make these decisions.[12]

Although the previous digital version was also browser-based, its logic was coded on the back-end, as mentioned, and ran only when a request from the browser was made. We discussed the 30-second timer loop that kept this going. It was necessary to have something trigger the changes seen on the screen.

In an SPA like this, the triggering event to update the display comes from within its own logic. Once triggered, the next set of code runs to perform the request to get data. As such, the server only serves data. I saw this new approach as a way to address at least two of the issues I was facing: (a) connection resiliency and (b) automation of the expiration of line-items. Although these problems could

[12] I would also like to note, each of these phases aren't always linear and step by step. However, as a practical matter of documenting the process, it's sufficient to organize the thinking in this manner.

have been solved in other ways.[13] This approach was crystal clear to me, and I knew how to achieve them.

The front-end would be the driver. It would make periodic requests to the back-end, asking for data updates, and continue to do so whether they succeeded or failed. Thus, built-into this mechanism is the concept of retrying upon failure (to address Internet and WiFi outages). The application's display simply remains the same while failures occur. Once the connection is successful, subsequently, it updates the display accordingly, if indeed the data has changed. As such, flaky Internet or WiFi connections are minimized.

When coding in Javascript for front-end applications like this, most developers leverage existing Javascript frameworks (a form of software library) to accomplish the task. There are several advantages in doing this. First, coding in pure Javascript would mean writing a lot more code, and with that implies equal amounts of additional testing. This is tedious and time consuming. Existing frameworks are well tested, support a vast set of browsers,[14] and allow the developer to focus on just the problem they are solving while keeping their code base as small as possible. Smaller code is easier to read and understand and work with, thus speeding up development time. However, the next challenge is in choosing the framework. There are several frameworks to choose from, each

[13] As in any software project, there are several ways to implement. I could have looked into creating a 'live' update mechanism via websockets as a way to push data from server to front-end, that would have made updates very smooth and eliminate the need for ongoing pull-requests. However, when it comes to resiliency against outages, a connection like this would still need to be reestablished by the front-end if it was interrupted. As such, a strategy like this would not have addressed the core resiliency problem I wished to solve (although it would have been an elegant solution for other reasons).

[14] Frameworks deal with differences in browsers (Chrome, Safari, Firefox, mobile vs laptop, small viewport vs large, etc.)

with their own set of trade-offs. This is the next-step in making technical decisions to proceed.[15]

Technical specifications for infrastructure and the back-end:

- For data-access, the system MUST use HTTP requests with JSON data payloads.
- The server SHOULD be kept as simple as possible; static JSON files are okay, although with the realization that this would later be swapped out for a better, content-management driven solution.

Technical specifications for the front-end:

- The app MUST leverage a framework that supports rapid development.
- It SHOULD be based on a popular, easy-to-use framework.
- It SHOULD be a ‘lightweight’ framework (over robust framework).
- The framework MUST support mechanisms (triggers) for maintaining a clock and periodic requests for data.
- The framework SHOULD support modular components for proper organization of the functionality.

For the Javascript framework selection, I chose ReactJS because of its wide acceptance and relatively lightweight footprint. Other frameworks are quite large and robust, with features well beyond what I needed in this relatively small application. Additionally, ReactJS is one of the most popular frameworks at the present time. It was created by Facebook and released into the public domain as

[15] In this iteration, I wanted to include the above specs for consistency with chapter Response Two. It’s more of a formality because most modern Javascript frameworks will have all the above features baked-in, although there’s the potential some micro-frameworks would only offer a subset of these features, but I don’t actually know that for a fact because I didn’t do exhaustive research to answer this question. I also felt I didn’t need to, because I had already reduced the candidate list of applicable frameworks to those that were robust enough to all of these cases.

an open-source project, available to everyone. Because of this heritage and wide adoption, development resources are abundant in many forms, both formal from Facebook as well as informal examples and unofficial documentation from other developers' own experiences. Additionally, I have had some exposure to this framework and I generally had a good idea how it worked. For these reasons, it made the most sense to go this direction.

First, there were a few infrastructural tasks to get out of the way before I started coding in earnest with the ReactJS framework. There was the matter of how to build and deploy the application to the server,[16] and setting up the server-side environment to accept it.[17] And there was the matter of how to serve data to the front-end's requests for data updates. These steps are well documented elsewhere, and out of scope for this document.[18]

Setting up how the server was to provide data required having a remote, in-the-cloud service deployed somewhere. This was easily accomplished with the same server I had previously provisioned (in AWS) for the older instances of this application. This saved me time. Expanding on this platform, and pre-existing web server software, I only had to make a few adjustments to serve-up this new content. I didn't even have to remove the old application! These two could run simultaneously, yet independently. The data were kept in JSON files, one for each day of the week. (This, of course, is a crude but simple way of managing the content and does nothing towards solving the content management issue.)

[16] ReactJS applications are packaged up in a small handful of files, 'wrapped' in a single HTML file (this the single page). Thus, these applications can be served by web servers on the initial request from the client front-end.
[17] The coding environment supports the means to package up the application. As for pushing that package out to the server, I had to set that up. This requires a little work in both the coding environment and on the server, to coordinate.
[18] One can begin learning about ReactJS from the official site at https://reactjs.org/, however there are numerous ways to read and find example code.

Although not absolutely required, I made one additional change for the added convenience it provided. I gave the server a name[19] on the network. I decided to do this because it made accessing this from the tablet's browser so much easier to remember. The previous method required remembering the IP address, which is not ideal.

With these tasks behind me, I was able to move quickly, developing the application code.

ReactJS supports the notion of components as a way to organize code. A component maps a body of code to a portion of the screen layout. Not that this application was bulky but this structure added a notion of elegance to the code. In the end, there were only three components, called 'App', 'DayAndTime', and 'Reminders'. A few additional blocks of code (source code files) were also included, to support working with dates and times.

'App' was the container that 'contained' the other two components, and was the component mapped to the entire display screen. Its associated stylesheet then would define styles scoped to the page. 'DayAndTime' was the header part of the layout, containing, as the name suggests, the day and time information. Its component stylesheet is then scoped to only the header portion of the layout. Finally, 'Reminders' was the body, the list of line-items comprising the set of reminders. Likewise, its stylesheet is scoped to the body or list portion of the layout.

In addition to implementing screen-wide layout concerns, the 'App' component also setup the update logic, defining two interval timers. One interval updates the day and time information. It fires every second, and passes the updated day and time data into the DayAndTime component, for rendering to the screen. I chose a one-second interval to avoid displaying any lag with the actual time. Although a

[19] A domain name on the web is the site name showing up in the first part of the web address (e.g., yahoo.com).

less frequent interval would have been fine, there was no real ‘cost’ to running this every second.

The other interval runs the data updates, and is set to a much slower interval. Each time this interval timer fires, it begins a process of (a) requesting data from the server, based on the day of the week (e.g., it would make a request for Monday.json if the current time was on a Monday), (b) populating its internal list, (c) determining if anything has changed, and, if so, (d) it would then call the ‘Reminders’ component to render the updated information. If the request for data failed, nothing would happen until the timer interval fires again, thus implementing ongoing retry attempts. It is only when the data is returned and has changed from before that the ‘Reminders’ component is asked to re-render that information. The framework makes these operations very efficient. The interval I chose while developing was six-seconds. This means, when I change the data, I have to wait at most six seconds before I see the change occur on the screen. In actual deployment this interval could be made shorter, such as 30 seconds, as in the previous implementation.

Back on the server-side, I would maintain a set of JSON files, Monday.json, Tuesday.json, Wednesday.json, etc., each day’s data in its own file. These files held the content (the list of items) as an array of data elements. To manage this data, I had to (a) log into the back-end server, ssh-style, (b) navigate to the folder where these files are located, and (c) edit the information as needed with a text editor and save. The editing process had to be done carefully in order to maintain proper JSON syntax. Any errors would render the file useless until fixed, and as a result no further data updates would be seen on the display until the file was fixed. As such, content management was very crude and esoteric, but sufficient for immediate needs.

RESPONSE: PART B: DESCRIPTION

Unfortunately, content management became even more dependent on technical skills. Changing content went from editing HTML files[20] to editing JSON data files. The latter is a less forgiving format, albeit more focused on data.

Due to my mother's changed circumstances, however, the displayed content had been dramatically simplified. Meals were very regular: they appeared the same for every day of the week. Caregiving visits, now done by staff, are high frequency and difficult to track in a pre-scheduled way. In my opinion there is low value in tracking these visits, even if we could. And, for the time being, our visits were left out of the mix. As you can imagine, the memory care facility where my mother lived had to operate very carefully during the COVID-19 pandemic. My brother and I were put on an essential caregiver list in order to be allowed access into the facility. We were the only family allowed to visit her.

Although my brother and I could have done a better job at planning our visits, and putting that information on the Reminders display, ahead of visits, we had not done so. This was partly due to the dynamic nature of our lives, and partly due to the extra esoteric work it placed on me in order to edit the content.

As a result, Reminders had a very static set of content, showing only meals, unchanging from day to day, during this five-month period.

OBSERVATIONS

At the time of this writing, my mother has been living in memory care for less than six months. Her operating memory is very poor. Although the move into memory care generally improved her mental condition, especially a reduction in anxiety, it did little to restore her cognitive capabilities. Out of curiosity, I asked her what she remembered about her previous apartment from only a few months

[20] Actually, these were snippets of HTML, not full HTML files.

back, and her experiences there. Although she had lived there about three years, at this point she had no recollection of it. She had no idea what I was talking about. With some prompting, I could get her to remember northern Wisconsin, but only a little. Her twenty-year experience living there prior to cognitive decline had a greater sticking effect. Better still was her ability to recall events of her childhood. The mind behaves strangely in this way.

The memory care staff took care of everything now. If my mother needed anything, such as a quick reminder to come down to the dining area to eat, they took care of it. Her meal schedule became very regular, always at the same time, every day. Staff visits occurred throughout the day, frequently, irregularly, and without much forethought in terms of a schedule. Visits from my brother and me were much less frequent than before, also irregular. She interacted with staff and a few of her fellow residents. These interactions became her new friends.

From a need or anxiety point of view, everything shifted. I had been working with the one trajectory I knew, and responded accordingly with the updates I had planned to make to Reminders. I basically continued the same path I was on, ignoring for the moment the huge shifts my mother was going through. I suspected she would need something other than what I had planned, but I did not know how, yet, until I had gone through the experience during this five-month period. I had to learn in review in retrospect how far off I was with this iteration.

In the previous period, my mother's focus and anxiety was primarily about food, and secondarily about people and visits. As such, during that period I had designed the items on Reminders to focus on food, even highlighting food over visits with the food icon. Visits were a secondary priority. Caretaker visits would fill out much of the rest of the display. Finally, visits from my brother and me were included, when we had enough forethought to put the information on Reminders. Family visits were the ones she sought after the most, so I made sure these were highlighted by adding color to the text.

During this period, in memory care, food was automatic and there was little need to worry or get anxious about it. There was also little reason or motivation to track visits from staff. Even if we were able to track staff visits, the value in doing so was extremely low. In any event, my mother had no anxiety about staff activity. Her new focus, with increasing anxiety, was about visits with family, especially from my brother and me.

When I redeployed Reminders to my mother's new apartment, the question about what to display was informed by these new conditions. Family visits should have been the priority, however, that data was difficult to manage—we did not have our act together. As a result we did not include family visits on Reminders during this period. Staff visits were inconsequential in her view, and accordingly left out. Although meals were extremely regular, the staff were eager to provide the needed reminder to come down and eat. Then what else could I display on Reminders if I did not want it to be blank?

I decided to display meals on Reminders, but because of the regularity of this information, the display was effectively unchanging except for the day and time. Reminders essentially became a clock with a written note. Since she had other clocks and no reason to look at the note, Reminders offered no new information. As a result, she stopped referring to it.

Visits from us became more irregular, partly because she did not require as much help from my brother and me. The staff did that. Because of the facility's COVID-19 restrictions, visits were made a little more difficult: the process of visiting required a call to provide advanced notice to the facility, donning additional protective equipment, and gaining access through the security doors. With reduced flexibility and decreased caregiving needs from us, we reduced the frequency of our visits.

Our visits were left out of Reminders because of their unpredictable nature, or at least until we could get our act together. I suppose, with more planning on our

part, we could have made a better effort to put these visits on Reminders. But as a practical matter, this was difficult to achieve without the ease of a reasonable content management system. Our failure to provide family visit information probably increased her anxiety. As a result, she frequently called us.

An emerging behavior during this period (and leading up to it) was her increasing fixation on our phone numbers, my brother's and mine. It was as if these numbers defined us in some way. We still allowed her to have a phone and make calls with it, but she no longer had a solid grasp on how phone calls really worked. She knew that she could sometimes talk to us by going through these procedures. Apparently, the procedure of making a phone call was enough of an engrained pattern for her to continue to perform these attempts. But she no longer understood telephone protocol. She just called and started talking, often leaving the latter half of what she said on my voicemail. Additionally, because of my mother's time-of-day disorientation, she made these calls at any time of the day or night.

Reminders during this period became ineffective for her. It did not fulfill any of her needs or address any of the anxieties she had. However, from a functional point of view, the device worked smoothly and nearly flawlessly. It became the device we would have wanted in the beginning, although still not perfect: new requirements and new ideas arise all the time, and those ideas will be discussed later.

Connection resiliency. The new functionality worked as intended. Outages were extremely rare. As of this writing, there have only been two outages within this five month period. When an outage occurred, I believe it was because someone, probably my mother, tried to use the device in some unintended way and could not find their way back to the application. I cannot verify this, but that is my guess. Technically, this system is now very solid.

Line items. Expiration of events worked flawlessly, too. Before, I had been making the equivalent updates by hand. Now, from a user's point of view, events expired when they should, and were done consistently.

Single page app: pros & cons. Because of the way the screen refreshed in the old application, the screen visibly flickered every 30 seconds. This would occasionally catch my mother's attention. At the time, I had not considered this a positive feature. The new application runs smoothly and without flickering. When updates occur, now, changes viewed on the screen are as subtle as you can imagine. The new application is slick, but I wonder if something more eye-catching should be displayed when updates are made to the screen.

From a developer's point of view, there are a few downsides to this new application. The opportunities for experimentation are reduced. Before, when editing HTML and associated stylesheets on the back-end, the display could be remote-controlled in a wide variety of ways, enabling all sorts of experimentation. Now, because of its data-driven nature, remote-controlling is limited strictly to the content. Layout and other content experiments must be done in code, and then re-deployed, which means someone has to be physically present with the display, and press reload on the browser.

At the conclusion of the previous iteration, there were several SHOULD-DO items mentioned that have not yet been addressed in this iteration. One, its name has not been reviewed. Two, scrolling or focus for larger lists has not been addressed. And, three, there has been little more thought about language and vocabulary choices.

Content management. Content remains difficult for anyone to manage, and nothing has been done to fix this as of yet, as already highlighted.

In summary, the device works even better than before. However, Reminders really no longer gets looked at because of the changes in my mother's care and

in how she directs her attention. She has shifted from an anxiety about meals to anxiety about family visits. She gets bored and lonely often. She forgets about visits afterwards, thereby exacerbating her sense of loneliness when people are not present. Upon return, she will claim she has not seen us for years.

Our mother calls us frequently with little regard to time of day or what we might be in the middle of doing. She will call again, even if she has just talked to us. Sometimes, when she is in a perceived state of panic, made worse by not getting through, she will continue making attempts in rapid succession. One day, she tried my number over 50 times. Other times, she might not call in a week. (At least the late night calls no longer concern me, since the staff is there to take care of any real urgencies.) We considered taking the phone away. I expect that would result in another anxiety. Rather than doing that, I have an idea that I would like to try first, based on the concept of the *adjunct mind*. I believe there are plenty of mitigations to be made yet to this system to keep it in-play for her current condition.

NEXT-STEPS & UPDATES TO THE BRIEF

Previously, my mother would focus her anxiety on food and meals. After her shift into memory care, she no longer has to think about it. Meals are fully taken care of, and staff provide reminders.

She also no longer needs to be concerned about caregiver visits. These items have already been dropped from Reminders and this practice can continue.

Conversely, her increasing anxiety about family visits could be better addressed by enabling these events to be put into the system. This requires an easy-to-use content management system, preferably mobile-enabled. Knowing when these events are planned would provide her with a greater sense of comfort. And she would be more inclined to use Reminders. Additionally, if Reminders could also

remind her, somehow, of recent visits, then maybe some of that anxiety could be reduced.

If there are no visits in a day, and meals would otherwise be absent from the display, what default activity should be presented? In my opinion, there should never be a blank screen, ever. A blank screen would begin to fade into the background. If it were to happen on several consecutive days, it could disrupt established patterns of continued viewing and perceived usefulness of Reminders. Blank screens, I think, would put its usage at risk. As such, if there are no other events to display, there should be some default content, ready to be displayed. In my mother's case, at least at present, this could simply be the meal schedule, as regular as it is. Additional research needs to be done to explore what other default displays would be helpful.

When it comes to phone usage, my mother has lost the notion of self-regulation, and to some degree the understanding about how phone calls function. Reminders could step in to assist in this area. I am suggesting the next area of exploration would be the integration of her phone with Reminders. I envision Reminders providing her relevant, real-time and historical feedback of phone calls. This feature would start when she first lifts up the phone's handset. Such a signal can be detected, electronically, and sent to the Reminders system. Reminders, in turn, can be coded to react in any number of ways in order to provide her with present moment feedback.

Initially, I see this as a 'pop up' message on the display. The system would have some notion of my brother's and my schedules, and know when we are at work or sleeping or otherwise preoccupied. It is my hope this feedback would enlighten my mother about why the call was not answered, or better yet, to interrupt the call in the first place.

For the historical context, this could include when past attempts were made, how many calls were attempted, and, if there was no answer, state the reason why.

Reminders could track the number of calls she is already made in the day, and their recentness (i.e., “you just tried to call Wade 3 minutes ago.”)

It is my hope that continual feedback like this would allow her to regain a better sensibility about appropriate phone usage. It is in the spirit of the *adjunct mind* to use Reminders to extend part of her memory, and inform her what she can no longer remember on her own. In this, it is my hope that she can regain some everyday normal function.

New requirements to be added to the Brief:

- MUST integrate Reminders with phones to provide contextual feedback.
- SHOULD track phone calls made.
- MUST implement a content management system.
- Content management SHOULD be mobile-enabled.
- SHOULD track past visits.
- SHOULD schedule upcoming visits.

Review and Analysis

In all of the stages of this project, the primary goal was aimed to mitigate my mother's anxiety by supporting her failing memory, filling-in core pieces of her day that otherwise she would likely forget. Prior to this work, my family's attempts to use unorganized notes, wall calendars, and random phone calls gained only small successes. It was clear something else was needed. Her anxieties emerged too frequently, and were slowly trending worse. I expected challenges along the way, but the reasons for doing this were always clear, and the basic metric was always the same: how has this system improved her experience at this stage in her life?

During each step of the way, I reviewed the effectiveness of each choice, technical or otherwise, in order to inform the next steps. Change was inevitable, I understood that. I expected her to decline over time. Unexpected were the influences of external factors, especially when the COVID-19 lockdown was thrust upon us, which caused my mother to experience profound isolation.

I responded to the changing requirements in four iterations. Each of these stages were initiated by an external force, motivating me to react and act quickly, to come up with a new design or adjustment to the design. I admit, there was probably more reaction than planful action. But the ongoing ideas and thinking about next-steps, in between, helped me when each next kick-in-the-pants happened. Then, I was able to react with enough thoughtfulness to make a difference when the call-to-action occurred.

Common wisdom says start with a paper prototype. Index cards were the first iteration. The first digital application—the second iteration—practically emulated what worked best from the index cards. The third iteration was more about adapting to a rapidly changing environment with the tools I had—adjusting

content as my mother's decline accelerated in the midst of a profound level of isolation, repercussions of the pandemic. Finally, a fourth and last iteration was made in an attempt to make everything run a little more smoothly, an attempt that coincided with my mother's move into full 24/7 memory care.

I like to think all this effort made a positive difference in my mother's life. There is evidence to support this. The first two iterations had the most impact. I saw confidence building and reduced confusion. I heard others' reactions to the changes in her behaviors. The third iteration also made a difference, but that felt more like a desperate chase. I was always always trying to catch-up to the next unanticipated condition. By the time the fourth iteration was done and deployed, it made little difference. She was already cared for by full-time staff: she was no longer required to perform any tasks. Everything was done for her. If there was anything I would have done differently, it would have been in the focus for this last iteration: a refocus of effort on easy content management in order to support dynamic changing of content. This would have enabled my brother and me quick ways to inform her of upcoming visits. While she no longer had to worry about meals, she did continue to worry about the people in her life that she needed to see.

In my work life, an agile coach (a scrum master) asks everybody at the end of a development iteration, "What have we learned?" The spirit of this idea lives in this project as well. At the end of each iteration I learned something about what was effective for the current conditions. Then, I applied those learnings to the next stage. Each time, I went forward with what I knew, the best I could. And each time, I came out of it knowing more.

The four iterations each started with an impetus, a tipping point. And each iteration had its context. As I responded to each of these four efforts, I observed and learned something. And, as a result, I acquired new knowledge that I could use to inform the next step.

Response 1. The first tipping point came when two circumstances collided. In my mother's cognitive condition, she had an unrealistic paranoia about one of us taking a trip and abandoning her. Second, I had actual plans for a lengthy international trip. The trip would interrupt the flow of frequent calls and interactions, create suspicions, and was likely to result in paranoia and anxiety. Borne out of the desire to mitigate these behaviors, I invented an index cards system that would become the first iteration of this project. This implementation replaced the unstructured and unorganized attempts with a structured information system based on index-cards on a simple brass letter rack. It also helped to inform her of every step of my travels.

The evidence of improvement came in a few forms. The consistency and predictability of this system helped quiesce my mother's anxiety. At this stage, she was able to navigate the cards in relative ease, and used the information contained therein. It helped her reestablish some semblance of autonomy and reduced her anxiety about meals. Besides observing an increase in autonomy and self confidence, the frequency of desperate phone calls made to my brother and me fell off dramatically. Building staff and other residents gave me their anecdotal stories, recognizing positive changes in her demeanor and behavior.

The index card system had an obvious positive impact on my mother. Ongoing, it seemed like more work on our part to create the materials and to keep everything consistent. While that work seemed burdensome, at times, to us caregivers, we should not forget to credit this system, indirectly, for a greatly reduced frequency of panic calls from my mother. In the balance, we saved a lot of anxiety-driven effort, paid for by our effort in maintaining the index cards.

The increase in self-confidence, as observed by many, was a surprise positive result we had not sought. In retrospect, however, it makes sense. With sufficient self-awareness, why would not someone who is sensing frequent undermining circumstances feel less confident, and by having this reversed feel more

confident? The index cards became a source of comfort. She came to realize these cards held critical day-to-day information, and therefore she recognized their value.

There is also an irony to the story. As the perceived value of the index cards increased, over time, the cards began to disappear more frequently. She started moving the cards to other, ‘more important’ locations, such as into her purse. This, of course, started to undermine the usefulness we had initially achieved: needed cards could not be found in their expected location. There is a Chinese sense of yin-yang duality in this, where the seed of the opposite is contained within. Although there were detrimental effects because of this behavior, and other minor shortcomings to this system, we were fully prepared to continue with it for longer than four months. However, another disruption changed those plans.

Response 2. The next tipping point would put me out of commission for months. My diagnosis came as a surprise, and with serious urgency. I had little time with which to develop another system, about two weeks, but I was able to create a digital version of the application that closely simulated the index cards. The new digital system addressed one significant shortcoming from the previous iteration, automation. The software-based system could now automate much of what was previously done manually. Additionally, its content could be remote-controlled, which would turn out to be a huge advantage given my post-surgery convalescence. All I had to do was pull out my laptop, connect to the back-end server, and change the content.

From my mother’s point of view, the content was pretty much the same. This is a good thing. The index cards were working well for her. Although she no longer understood how the messages were getting on screen, she came to trust the system as some kind of external authority. Before, with index cards that I obviously hand-made, she connected me with the activity. This became

disconnected with the digital system. Upon visiting her, she would often ‘introduce’ me to her reminders display.

One immediate side-effect of installing a 10-inch tablet on a stand, next to her phone, to replace index cards, was that it was much more difficult for it to go missing. With that problem solved, her go-to location for to-do information was always the same. Consistency was always a useful tool when working with my mother in this stage of cognitive decline. And I was to learn this lesson again in the next iteration.

We had been running with the initial digital application for about four months in iteration two. This period was defined by a new digital application and consistently executed content, designed to mimic the index cards. The most defining features of this new system was the ease of changing content remotely. As such, the incremental improvement from my mother’s perspective over the previous card-based system was small. Although small to her, it was a huge difference to us caregivers. As a result, she had a better system since it was always more up-to-date, automatically changed to appropriate content day by day, and displayed consistently from one location.

Response 3. While the beginnings of the first two iterations of this project were each clearly demarcated by the creation of a new system, the threshold between the second and third iterations was blurred because these two phases were running with the same digital application. What was different between these two periods, however, was the COVID-19 lockdown and isolation my mother experienced as a result. Therefore, the third iteration begins mid-March 2020, at the start of the lockdown.

Iteration Three is characterized by my mother’s accelerating decline during this period, and my attempts to compensate for the decline with content changes, some experimental. Also during this period I named the system Reminders and reinforced its name visually, at the device. While naming seemed like a small

thing, it lifted a cumbersome burden when trying to refer to the device during conversation. It was especially important to refer to a name while in conversation with her on the phone. With its given name, I had a much better chance at directing her attention to it when I needed to do so.

I spent much time carefully considering how to present content. Some ideas were reductionist, like the choice of language. The goal was to achieve as much clarity as possible and reduce the potential for confusion. This was an ongoing effort, continually catching up with her changes, or sometimes just dealing with an occasional bad day. Also during this period her ability to understand abstract concepts was in decline. As such, I sought for the simplest terms to use, and attempted to keep everything in the present and always concrete.

Other experiments were about attention-getting, or ways of introducing a little fun into the system with imagery. Most of these experiments fell flat, but making these experiments provided a good counter-example in validating the above theme: keep the interface as simple as possible.

One of the content experiments was a great success: expiring past events by adding text treatments to gray-out and strikethrough. Without this treatment, my mother did not know the appropriate time context—she would read through the day's events top-down, even if it was late in the day. After applying this treatment to expired events, she immediately knew where to look for unexpired events.

Since I was doing this manually, by editing HTML, it was a lot of work to keep up. This was a big motivation for me taking on the effort to rebuild the application for the next iteration. The other motivating factor was to fix the ongoing connection flakiness.

Meanwhile, my mother was soon in the process of moving into memory care. Although it was not clear, yet, what she would need from a device like this while living in memory care, I continued the pattern of responding to the results of what

I learned in the previous iteration, and applied those changed specifications to the next iteration.

In total, the third iteration lasted about seven months, all the months from the beginning of COVID-19 lockdown, March 2020, to when she moved into memory care in October.

Response 4. The beginning of the fourth, and last iteration[21] was marked by two significant events: I rewrote the application, and my mother moved into memory care.

Unfortunately, this story ends in bittersweet misfortune, an ironic tragedy in the literary sense. Nothing serious happened except unfortunate timing. Unsurprisingly, her new living conditions obsoleted the need for Reminders right when Reminders achieved a stage of tremendous (theoretical) usefulness. She no longer looked at it.

For the fourth iteration, the application was rebuilt more thoughtfully towards fixing a few substantial infrastructural problems. However, in the end, because of my mother's changed circumstances and concomitant changes in her needs, she no longer needed what Reminders could do best—remind her of meal times. With her basic needs addressed by memory care staff, she was now fixated on family visits as a new source of her anxiety. This activity was more difficult to manage with Reminders because of the lack of content management features. An easy-to-use content management system would enable family caregivers to easily inform her of upcoming visits.

This stage of the reminders system came full circle: it effectively became useless for addressing my mother's needs at this stage in her life. However, this experience has set in motion new ideas that should be expanded on.

[21] This would be the last iteration for the study, however plans are in place to continue the work. For the purposes of this study, I draw the line at four iterations.

Ideas for future expansion are discussed in the next chapter. It is my expectation that further enhancements, if timely done, will again make Reminders useful for her, and more generally useful for others in similar condition.

I have noticed a few patterns during these past few years.

In particular, isolation was a noticeable accelerator of my mother's cognitive decline while living in the house in Wisconsin and again during COVID-19 lockdown. In both cases, socialization and interaction with familiar people was the antidote.

Her cognitive decline manifested in several ways, including memory loss, poor decision-making, and paranoia. These conditions, in turn, led to an increased level of anxiety and a reduction in self-worth and self-confidence. Regaining a perception of regularity, structure, and predictability helped reverse her anxiety and promote self-confidence and self-worth.

Taking a page from Maslow's hierarchy, not understanding how and when food and meals were managed resulted in a perception of unmet basic needs. Once those needs are met, as her perception goes, the concern for belonging and family becomes the prime focus. This would suggest a system like Reminders could adapt to these changing needs and perceptions, as long as the perceptions could be identified. For my mother, any perceived threat to her safety was a rare occurrence, and it is difficult for me to interpret which of her past behaviors were possibly a result of this type of threat. I bring up the topic of safety because it is the second tier above basic needs (e.g., food) and below belonging (family connections) at the third tier.

Now in memory care, her basic and safety needs are fully cared for by the staff. She has some social interaction with the staff, and some with other residents, but these relationships do not go deep. For a deeper relationship, she looks to family,

especially visits from my brother and me. This is clearly the next endeavor with Reminders in the case of my mother.

Generally speaking, however, Reminders could be constructed to adapt to the needs observed. This will be the topic of the next chapter: how could Reminders expand and generalize for others' use?

Conclusion and Future Expansion

With this project my vision was to improve my mother's quality of life while postponing her move into institutionalized care. In doing this, it was my hope to reestablish some semblance of her former independent life when her mind was sharp and her attitude self-reliant. I chose to mitigate her cognitive decline by supplementing her mind with external aids, leveraging technology. I established the phrase *adjunct mind* to signify the concept of employing technology as an extension of mental activity, potentially replacing what had been lost. The critical piece in this work, however, is in how the user can interact with the technology. Otherwise, the most sophisticated system will have no benefit if the user cannot use it. Thus the challenge of this project lies with how to effectively communicate, using this system, with a user whose cognitive abilities are in decline.

This project evolved through three overarching phases, loosely defined by what has motivated the work. The project began solely in response to my mother's decline. In the middle of the project's second iteration, inspired by the advice of others, I shifted the project into an academic study. Later still, I came to understand how this system could be generally useful to others, and possibly made into a service or product.

EVALUATING SUCCESS OF THE PROJECT

Designing and implementing Reminders during the twenty months of this project has been continually challenged by changing conditions. Dementia is a progressive disease, but this continual influence on my mother's cognitive decline was only part of the story. Environmental factors played a huge role during this period. In particular, four events defined the beginning of each iteration. Factors in my own life were the impetus for starting each of the first two iterations. The COVID-19 lockdown defined the beginning of the third iteration.

The ongoing effects on my mother during the lockdown resulted in an accelerated decline due to her profound isolation. This ultimately led to her undoing, and the beginning of the fourth iteration: moving her into memory care.

At the outset of each iteration, I had expectant goals: to improve the quality of my mother's experience while at the same time reduce the burdens her care had on the rest of us.[22] Each time, I was met with varying levels of success. As crude as the first two iterations were, these were the most successful. These iterations helped her regain confidence and reduce her anxiety. The third iteration yielded incremental improvements during the COVID-19 lockdown. These improvements were directed at mitigating her significant decline during this difficult period. In the end, these three iterations helped my mother cope, and helped us caregivers manage her life. Many positive impacts were anecdotally observed by myself and others.

This project made a significant difference in my mother's experience. I believe I achieved the goal of postponing institutionalized care while maintaining a quality of life she could enjoy. We could have justified moving her into institutionalized memory care instead of her apartment building in the original move from Wisconsin. Her functional assessment numbers at that time would have supported that decision. Yet, through the work of this project, she lasted three years in the independent living senior apartment building.

The fourth iteration was another matter. Although the reimplementation of the code for this iteration solved many of the issues identified from the previous iteration, the product of this effort went unused. By this time, my mother had been moved into memory care. The staff in the care unit provided all that she needed. She no longer had anxiety about food, as was often the case back at her apartment. As such, she no longer needed to look at Reminders. Had she stayed

[22] For example, reducing her level of anxiety reduced the number of panicked phone calls we needed to respond to. When we needed to respond, we could update her note remotely, eliminating the need to drop everything and rush over there.

in independent living, however, I believe the new features would have been immensely helpful. It was bad luck at timing, and the fourth iteration did nothing to help my mother, but I consider these changes good closure to the project itself.

There is not much I would have done differently, if I had to do it over again. Getting a sense of closure from the work of the fourth iteration was fine. A better result would have been to address other, anticipated issues as a result of my mother's move into memory care. The work done in the fourth iteration extended features focused on displaying the day's events, but my mother no longer required those features. Instead, my mother's new source of anxiety was about family visits, and staying in touch with family. Redirecting efforts towards those features would have kept Reminders active in her life. This work of course can still happen outside the scope of this project.

GENERALIZE TO A WIDER AUDIENCE

Cognitive decline represents many millions of cases across the world. There is a lot of effort studying and understanding the effects of this condition. The scope of the problem is vast in the number of cases. In some cases, the severity of decline places significant burdens and costs to all levels of society from individual to institutional.

Many products have been created to assist in the care of these individuals, but mostly these products are directed at caregivers as the end users. Of the products that directly target people with cognitive decline as the end user, many are of the brain exercise genre, and only a few attempt to support daily living activities. Examples of this are products that help those in decline to identify their caregivers or, like this project, support the tasks of daily living. In my ongoing search for existing equivalent products, I have so far found two ad hoc projects, and one research project whose scope suggests its aim is within an institutional setting. This represents a huge gap.

Although my mother is just one case of millions, this work is easily generalizable to a wider audience. I accept there are biases within this project, such as word-choice to fit my mother's vocabulary, but such choices are only a matter of adjusting the content. Another built-in bias to the project was my mother's gradual acclimatization to the digital version via index cards. If this were indeed a concern for general usage, a training-in period could be constructed with similar cards. Studying whether this is necessary would be a reasonable follow up activity towards generalizing this product.

I believe applying this system to others with cognitive decline would offer similar benefits experienced by my mother. I already see great potential based on my own observations and from the anecdotal observations of others. During the four iterations and twenty months of this project, I have spoken to several people. Hired caregivers have observed it directly, and some have given me feedback. For others, I have only described it. In each of these cases, their responses have been positive or encouraging in one way or another. Some comments are validating, like, "That's a good idea!" Some people have a greater interest and say, "I could use that!"

This system offers potential benefits to those experiencing cognitive decline in ways similar to how our family benefitted. The goals for everyone are the same: to reduce confusion and anxiety, to clearly and simply inform, and to enable a means for caregivers to manage and fine tune the messaging for their loved ones. Generalizing this product to a wider audience will require more study to better understand how its individual features will benefit the end users, and where to focus on product improvements.

The needs of others will vary as a function of the degree of cognitive decline. Those who are mildly affected by decline would begin to benefit while at the same time acclimatize to using and depending on such a device.

My personal plans include improving upon Reminders to once again help my mother. I believe there remains a use case while she is in memory care. I believe she would benefit by knowing when someone will visit, but I will need to study this case a little further before implementing the needed changes.

Furthermore, as a general feature, not necessarily targeted for my mother, I am looking to update the design to better contextualize the current time with the upcoming event. These changes will undergo some sort of research. I believe I have a firm foundation on which to build features to serve anyone experiencing cognitive decline.

This period has been an immersive learning experience for me in designing, implementing, and deploying this system. Experimenting with simple targeted designs and vocabulary has given me added appreciation about the subtleties of the use of language and its position upon the page. Through the project, the research and the literature, I have learned to see this issue more holistically and from several perspectives.

EXPANSION ON RESEARCH

Just in the past couple of years I am seeing more study in this area, especially in Europe. I am excited to see where this will lead. I can imagine, eventually, a new design reference will emerge on principles of design for use with anyone cognitively challenged, perhaps in concert with the work with accessibility.

Further study is needed about design communications, with people experiencing cognitive decline. I am also curious about metrics to measure the efficacy of assistive devices. Like functional assessments, only more on-the-fly and immediate, I wonder how to determine or measure someone’s cognitive level, and to recognize a change in either direction, or recognize individual patterns. This information could then be used to adjust the user interface dynamically. Last, I would like to see how language skills and vocabulary change with decline

at an individual level. If this can be done, the results could be used to adapt the language used within the user interface.

Postscript

My design decisions throughout the implementation phase of this project were intuitive, and not following any sort of rule book. While documenting the project, however, I have found Universal Principles of Design (Lidwell, Holden, & Butler, 2010) to be a useful tool for understanding the choices I made. Many of these principles are common sense put to a more formal description. In particular, of the five organizing principles in Five Hat Racks, I have been organizing information primarily by Time. Category would be another appropriate method. The other three methods (Location, Alphabet, and Continuum) require abstract thinking beyond what I think we can safely assume for this user audience. Even now, as my mother's decline continues, I am starting to question the use of Time as a way of organizing the information. Her sense of time is fading. Perhaps that is soon to be too abstract as well.

The choice of language is of increasing importance for this user population, especially as the user continues to decline. One must go for minimalism and obviousness for the broadest possible application. The Readability principle (Lidwell, Holden, & Butler, 2010, p. 198) reads, "the degree to which prose can be understood, based on the complexity of words and sentences." My experience with this project has shown me there is no more apt principle to act on than this one. When things went badly during COVID lockdown, I struggled to come up with the right words, and I was often surprised by how some of the simplest terms were no longer understood by my mother. This progressive disease continues to shrink my mother's universe, decreasing her capacity to understand. For continued user-interface effectiveness, the language choices must be adaptable down to the simplest possible core.

Familiarity turned out to be another extremely useful principle in this project. This topic is touched on in Universal Principles of Design in the description of the

Exposure Effect (Lidwell, Holden, & Butler, 2010, p. 86), however, this principle is more focused on likability as a result. For people with cognitive decline, the emphasis changes from likability to basic functionality. If one were to come up with a list of design principles for cognitive decline, Familiarity would need its own place on the list.

Without knowing it at the time, the use of index-cards prior to the digital implementation was a type of training for my mother, leveraging her familiarity with notes on paper. Then, later, the project moved into the digital realm, leveraging her new found familiarity with index cards.

Calendars and schedules were a big part of my mother's life for a long time at her work. Afterwards, in retirement, the use of these organizing tools remained in her life. By the Familiarity principle, I argue that organizing information by Time was more accessible to my mother because of this experience. Many people continue to use these tools, so I would expect similar results for others. But even this didn't last for my mother: the concept of time itself became blurred for her. As her decline continues so must the user-interface adapt to accommodate the decline. For my mother, perhaps we are at a stage where a single item appears without any time information (in a time appropriate way).

This reinforces my thinking about adaptive user-interfaces. As the decline proceeds, not only does the language need to adjust and become simpler, but also the amount of information, eventually, down to a single bit of information. It could say "It is Lunchtime" or even just "Lunchtime" when noon is about to arrive. Adaptability would be another principle on the list of design principles for cognitive decline. Cognitive decline doesn't nullify universal principles of design, but the needs are more focused. The principles are reduced down to their simplest forms for basic understanding.

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